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High Risk Infant Identification System
1985 Annual Report

Massachusetts Department of Public Health
Division of Family Health Services

HIGH RISK INFANT IDENTIFICATION SYSTEM

1985 ANNUAL REPORT

Prepared by the Massachusetts Department of Public Health,
Division of Family Health Services

May 1988

The Commonwealth of Massachusetts
Michael S. Dukakis, Governor
Philip W. Johnston, Secretary, Executive Office of Human Services
Deborah Prothrow-Stith, M.D., Commissioner
Department of Public Health

FOREWORD

The Commonwealth of Massachusetts has historically recognized the importance of the early identification of infants at risk for higher mortality and morbidity. This led to the passage of the Premature Infant Law of 1937 (Chapter 111 Section 67 A-D) which was written to influence and monitor the care provided to low birthweight infants (weighing 5 1/2 pounds or less).

Over the last forty years, other laws mandated subsequent reporting systems to monitor infants born with congenital anomalies, prematurity, and those at risk for hearing loss. These systems were incomplete and lacked uniformity. Our current High Risk Infant Identification System was developed to consolidate the existing reporting methods, integrate data collection, and to more actively and comprehensively identify infants at risk for developmental, neurological and physical dysfunction.

We are pleased to publish the first annual report of the High Risk Infant Identification System. The purpose of this report is to provide data documenting regional patterns in the reporting of high risk conditions, variation in prevalence, and patterns in the management and referral of infants with high risk conditions. In its preparation, we have attempted to present the data in a meaningful way for regional DPH staff, hospital personnel, and legislators concerned with the health and development of infants born with high risk conditions.

Nineteen eighty-five represents the first full year of data collection for the HRIIS. As such, these data are limited in their completeness and accuracy. The disparity between the reporting levels in various areas of the state should not be mistaken for evidence of differences in the quality of care or type of population, etc. Rather, these data are the result of the newness of the HRIIS in 1985 and underscore the need for hospitals across the state to strengthen their commitment to the system and to greatly improve their level of reporting.

The staff of the HRIIS is also taking steps to upgrade and expand reporting. **However, until these efforts are fully realized, it should be clear that the data are limited in their applications and must be referred to only within the context of this document.**

This Report has been the joint effort of several Division of Family Health Services staff. I offer my thanks and congratulations to those who have made the production of our first Annual Report possible.

Serena Mailloux, M.D.
Director, Perinatal and Genetics Unit
Division of Family Health Services
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EXECUTIVE SUMMARY

In 1986, legislation revising the Premature Infant Law of 1937 mandated the Massachusetts Department of Public Health to develop and implement a statewide High Risk Infant Identification System (HRIIS). The goals of the System are to:

@ develop, refine, and maintain a comprehensive data system of newborn infants reported to be at risk for developmental, neurological and physical dysfunction;

@ monitor the neonatal transfer system, referral patterns and services available for high risk infants;

@ promote the early identification of infants at risk and their entry into a system of services which will support their health and development; and

@ provide a mechanism for complete and accurate reporting of birth defects.

Accuracy and completeness of reporting to the HRIIS requires active and effective working relationships with hospital personnel. The central HRIIS staff include a data manager, coder, and regionally-based perinatal nurse coordinators. All have a crucial role in the development of a comprehensive data system that can provide the information and assistance necessary to promote continuity of services available to high risk infants and their families.

The publication of this Report provides the most current annual compilation of the HRIIS data. We have progressed toward a fuller understanding of the System's limitations and have noted where improvements can be made. We will continue in our efforts to upgrade the HRIIS. Our success depends on strong cooperation with hospital personnel who can be responsive to our need for accurate and timely reporting.

This document is divided into several sections for easy reference: characterization of high risk conditions; transfer and referral patterns for infants with HRIIS conditions; special reports on the Hearing and Evaluation Program for Infants and Toddlers, and on congenital anomalies; and lastly, quality assurance. The data reflect the early development of the HRIIS. **As with any new reporting system, the data are limited in their completeness and quality. The data presented in this Report describe only infants reported to the HRIIS in 1985 and therefore are not representative of the entire population of 1985 births to Massachusetts residents.**

Characterization of High Risk Conditions

@ In 1985 6,170 infants were reported to the HRIIS, representing 7.5% of all resident live births in Massachusetts.

@ Among the twelve criteria selected as identifiers of newborn infants at risk for neurological, physical, and/or developmental dysfunction, the most commonly reported were: birthweight $\leq$2500 gms, more than 24 hours in NICU setting, family history of hearing loss, congenital anomalies and assisted ventilation. These five criteria account for 89% of all high risk conditions reported.

@ Although low birthweight is one of the most commonly reported HRIIS conditions, there is significant underreporting on the 1985 HRIIS forms. In 1985 4,750 birth certificates were filed for infants with a birthweight of $\leq$2500 grams compared to 2,961 low birthweight infants reported to HRIIS.

Transfer and Referral Patterns for Infants with HRIIS Conditions

@ Over 45% of all infants reported to the HRIIS were transferred to a Neonatal Intensive Care Unit (NICU).

@ Among the infants transferred to NICUs, most (73%) were born in and transferred to a NICU within the same hospital.

@ Half the number of HRIIS infants admitted to NICUs were discharged from NICUs to their homes. Forty-three percent were transferred to either a community hospital or an in-house normal nursery. Six percent of HRIIS infants in NICUs died.

@ Mean Length of Stay (LOS) for infants who were not transferred to a NICU was 5.1 days compared to 17.5 days for those who were admitted to a NICU.

@ 25% of all infants reported to the HRIIS were referred to community services for follow-up care.

Special Report: The Hearing Evaluation Program for Infants and Toddlers

@ The Hearing Evaluation Program for Infants and Toddlers is designed to: identify infants and young children at risk for having or developing a hearing loss, inform parents about the importance of hearing to an infant's development, and provide access to specialized audiological evaluations to at-risk infants.

@ In 1985, 2,906 infants at risk for hearing loss were reported to the HRIIS.

@ Eight risk factors were selected to identify infants and toddlers at risk for hearing impairment. All of these conditions are reportable to the HRIIS. Massachusetts residents are eligible for the program from birth until age three if they have one or more of these risk factors. The most commonly reported high risk conditions associated with hearing loss were: family history of hearing loss (37%), birthweight less than or equal to 1800 grams (23%) and assisted ventilation (16%).

- In 1985, 794 infants with congenital anomalies were reported to the HRIIS, with a total of 920 anomalies.

- Compared with data on ten anomalies from the Centers for Disease Control Birth Defects Monitoring Program, anomalies that were most completely reported to the HRIIS in 1985 include: cleft lip with or without cleft palate, limb reductions and Down syndrome. The most underreported congenital anomaly was anencephaly.

- Low birthweight infants (≤2500gms) have higher rates of congenital anomalies than do normal birthweight infants (>2500 gms).

- Premature infants (<38 wks) have higher rates of congenital anomalies than do normal-gestation infants (38-42 wks) in all categories except ear, face and neck, and integument.

- The Department of Public Health has plans to establish a Congenital Anomaly Surveillance System based on data obtained from the HRIIS and birth certificates. The system will be used to identify trends in the frequency of birth defects over time and in different communities; to facilitate research into the possible existence of new teratogens or increased exposure to old ones; and to facilitate public health planning of genetic services for the early detection, treatment, and possible prevention of birth defects. It is expected that this system will become operational in 1988.

Quality Assurance

The process of capturing all information on the HRIIS reporting form is complicated by many factors. The quality assurance measures for the HRIIS were designed to:

- revise the HRIIS reporting form with more clearly defined criteria to improve data collection;

- refine protocols for collecting and processing data;

- provide more comprehensive training, data and information to hospital staff to improve the quality and level of reporting; and

- determine the accuracy and completeness of reporting for certain high risk criteria.

These measures will be more fully addressed as reporting to the HRIIS improves and more data become available.

I. INTRODUCTION

The High Risk Infant Identification System (HRIIS) in Massachusetts is a legislatively mandated, statewide reporting system which identifies newborn infants who are considered to be at risk for neurological, physical, and developmental dysfunction. The HRIIS is a component of the High Risk Infant Program within the Perinatal and Genetics Unit of the Department of Public Health, Division of Family Health Services. The overall purpose of the High Risk Infant Program is to promote and strengthen the maternal and child health care network in the Commonwealth through the early identification of high risk infants and their families and by facilitating their entry into the system of services.

The HRIIS promotes the mission of the High Risk Infant Program by providing a comprehensive database with which to review and assess neonatal care, mortality, and morbidity. The information reported to the System provides an epidemiological picture of the prevalence of certain neonatal risk conditions, their geographical distribution, and the types of services offered to the families of these infants. Thus the goals of the High Risk Infant Identification System are to:

@ Develop, refine, and maintain a comprehensive data system of newborn infants reported to be at risk for developmental, neurological and physical dysfunction;

@ Provide a tool for monitoring the neonatal transfer system, referral patterns and services available for high risk infants;

@ Promote the early identification of infants at risk and their entry into the system of services which will support their optimum health and development;

@ Provide a mechanism for complete and accurate reporting of birth defects.

The first Annual Report of the HRIIS is intended for hospital personnel, MDPH staff responsible for implementing and monitoring the system, and others concerned with improving the early identification of high risk infants. It is divided into several sections for easy reference. Tables and graphs are included throughout the Report. **The data reflect the early development of the HRIIS and we must caution against misinterpreting or over-generalizing the data.** As the quality assurance measures discussed in Section VII are implemented, the level and accuracy of reporting to the HRIIS will increase.

II. BACKGROUND

A. History of the HRIIS

There have been several mandated reporting systems in Massachusetts to influence and monitor the care provided to infants at risk for increased mortality and morbidity. Systems were created for the reporting of premature infants, infants with a congenital anomaly or birth injury and infants at risk for hearing loss. Until 1982, each of these remained distinctly different in its purpose and procedures for data collection and monitoring. Data were not collected in an integrated or usable format and many infants who should have been reported to the various systems were not. In 1982, legislation was first introduced to revise the existing Premature Infant law of 1937 and the amendments that followed. This legislation provided for the development of a reporting system to consolidate and expand the three existing reporting methods under what is now the High Risk Infant Identification System (HRIIS). We began collecting data in 1984 and final legislation for the HRIIS went into effect in 1986 (see Appendix A).

B. The HRIIS Form

High risk infants are identified at birth and during the neonatal period through mandatory reports from maternity units and neonatal intensive care units (NICUs) in Massachusetts hospitals. A simple codable form was developed for the HRIIS which requested information reported by the previous systems and added other criteria to identify high risk infants and to obtain follow-up information as well (see Appendix B). In all, fifty-eight hospitals with obstetrical units and eight neonatal intensive care units were oriented to the system. The Women and Infants Hospital in Providence, Rhode Island, where some Massachusetts infants are born and to which some high risk infants from Southeastern Massachusetts are transferred for tertiary care, was also oriented to the system.

Twelve criteria were selected as identifiers of newborn infants who are at risk for neurological, physical and developmental dysfunction. These are:

1 birthweight of 2,500 grams (5 lbs. 8 oz.) or less;

2 severe growth retardation;

3 more than 24 hours in a NICU;

4 assisted ventilation for 24 hours or more;

5 seizure(s) or neurological abnormality;

6 intraventricular or cerebral hemorrhage;

7 APGAR score of 5 or less at 5 minutes;

8 congenital anomaly(ies) (includes all structural, chromosomal, genetic, and biochemical defects or syndromes);

9 exchange blood transfusion for hyperbilirubinemia;

10 meningitis or congenital infection;

11 a family member who has had a hearing loss since childhood.

12 a mother who had rubella, toxoplasmosis, cytomegalovirus, or genital herpes during pregnancy;

The HRIIS form includes descriptive information about the high risk infant, the infant's current status, transfer of the infant from one level of care to another, and referral to the primary care provider and other services upon final discharge of the infant from the hospital. Thus, the High Risk Infant Identification System is able to identify:

@ infants reported to HRIIS who are at risk for developmental, neurological, and physical dysfunction;

@ patterns of infant transfer and referral in order to assist in planning for regional services on behalf of high risk infants and their families;

@ infants at risk for hearing impairment in order to ensure that all such infants have an opportunity to register with the MDPH Hearing Evaluation Program for Infants and Toddlers;

@ newborn infants with birth defects in order to determine the baseline prevalence of congenital anomalies in Massachusetts.

C. The Reporting Process

Each maternity and newborn service in the Commonwealth is provided with a supply of HRIIS forms, each form having three color-coded pages. A flow chart representing the reporting process is included in the Appendix.

The pink, first sheet is initiated by the birth hospital if a high risk condition is detected during birth, post-natally, or known to exist prior to birth (e.g., family member with history of hearing loss or mother who had rubella, toxoplasmosis, cytomegalovirus, or genital herpes during pregnancy). A HRIIS form is usually completed by a nurse in the nursery. When the newborn is discharged from the hospital of birth to a parent or guardian, that hospital is responsible for completing all of the information on the form.

If a high risk newborn is transferred to tertiary care in another institution or to a NICU in the same institution, the pink sheet is completed by the birth hospital to the extent possible, including transfer date, and is then forwarded to the Massachusetts Department of Public Health (MDPH). The other two pages of the form are included in the medical record that follows the infant to the NICU.

At the NICU, any newly detected high risk conditions are noted on the green, second page of the form. The NICU is then responsible for noting

the date of discharge and any transfer to a community hospital, to an in-house normal newborn nursery or discharge to parent or guardian. If an infant is transferred to another NICU, the name and discharge date from the second NICU replace those recorded from the initial NICU thus allowing the determination of the total length of stay in a NICU or tertiary care environment. This green page is then detached and sent to the Department.

If an infant is transferred from a NICU to an in-house normal nursery or to a community hospital, that hospital or nursery becomes responsible for the remaining items on the form. These include the discharge date, discharge status (home to parent, adoption, foster care), the primary medical care provider, any special medical follow-up and any referrals, such as to a community nursing agency or Early Intervention Program. These data are recorded on the third part of the form (blue) and forwarded to the Department at the time of discharge. Reporting to the HRIIS ends when the infant is discharged to a parent or guardian.

The parents of all high risk infants are given a brochure describing the system, the criteria for inclusion and the address and telephone number of the HRIIS Perinatal Nurse Coordinator in their local DPH office for more information.

D. Central Staff and Regional Coordination

In 1985, the HRIIS staff included a data manager, coder, and three perinatal nurse coordinators. The data manager is responsible for the processing of all HRIIS reporting forms. The data manager also maintains the computerized file of high risk infant data, including writing programs for data analysis. In addition, the data manager is responsible for the preparation and distribution of regular data reports and other statistics which are used by regional and central staff to assess the status of the system.

The HRIIS coder is responsible for reviewing all HRIIS forms for errors and omissions. The data are then coded for congenital anomalies, other high risk criteria, and descriptive information where indicated. The coder also works with the data manager in the production of statistical reports and data requests.

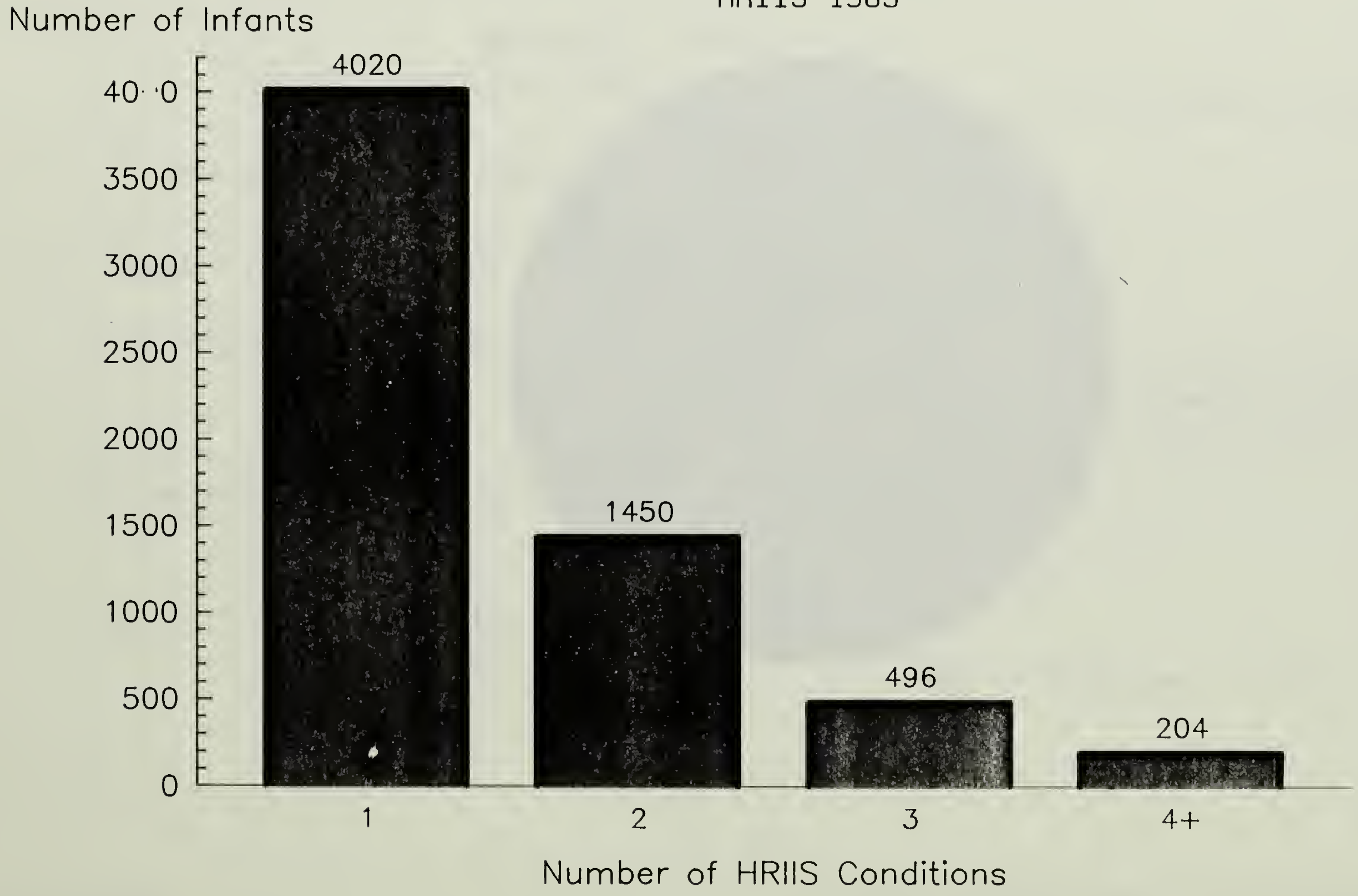
The nurses serving the Southeast, Northeast, Central, greater Boston, and Western regions of the Commonwealth are responsible for maintaining active and effective working relationships with hospital personnel in order to ensure accurate, complete, and timely reports of high risk infants. They provide training and technical assistance to hospitals regarding the high risk infant reporting process and the development of the hospitals' procedures for completing the forms. They are responsible for obtaining any missing data and incomplete forms from hospitals in their assigned region. The nurses also work with community-based health care providers, regional MDPH staff members, and others regarding maternal and child health issues, including infant mortality, nutrition, breast feeding and home-based nursing care. These working relationships strengthen the bonds between community, regional and state maternal and child health programs and providers.

III. CHARACTERIZATION OF HIGH RISK CONDITIONS

Each High Risk Condition as a Percent of all Conditions Reported to HRIIS

In 1985, 6,170 infants were reported to HRIIS representing 7.5% of all live births in Massachusetts (81,776). An infant reported to HRIIS may have more than one condition. In 1985, 4,020 infants were reported with just one condition; 1450 were reported with two; 496 were reported with three, and 204 were reported with four or more (See Graph 1). The 6,170 infants reported to HRIIS had a total of 9,429 conditions. The most commonly reported high risk conditions were: birthweight $\leq$ 2500 gms (31.4%), more than 24 hours in a NICU setting (27.9%), family history of hearing loss (13.4%), congenital anomalies (9.8%) and assisted ventilation (6.5%). These five criteria account for 89% of all high risk conditions reported (See Graph 2).

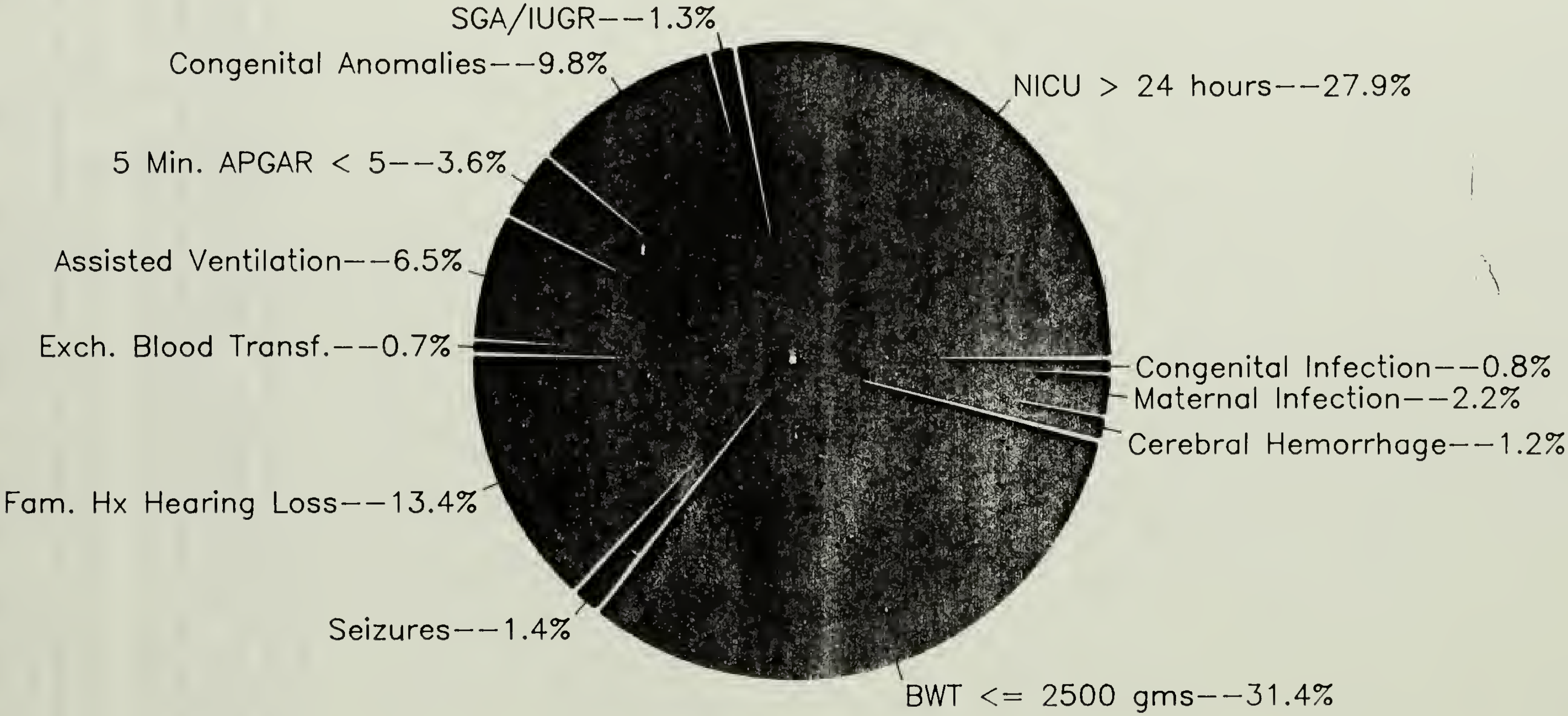
Graph 1
Infants Reported to the HRIIS with One or More HRIIS Condition
HRIIS-1985



Data Source : Division of Family Health
Services, DPH

Graph 2

Percent of Conditions reported to the HRIIS
HRIIS - 1985



Data Source :
Division of Family Health Services, DPH

Note : N=9429. This is a duplicated count. More than one HRIIS condition was reported for some infants.

Conditions Reported to the HRIIS by HSA of Birth Hospital

Massachusetts is divided into six health service areas (HSAs) for the purposes of planning and developing health services. Each HSA encompasses both metropolitan and non-metropolitan areas. Appendix D contains an alphabetical listing of Massachusetts cities and towns with their corresponding HSAs. HRIIS data from 1985 are reported by HSA rather than individual birth hospital or town of maternal residence because of the known incompleteness of the first year of data collection.

The reported HRIIS conditions are tabulated by HSA of birth hospital in Table 1. Listed are numbers of conditions rather than infants. The number of conditions is larger than the number of infants since an infant can have more than one HRIIS condition. HSAs III and VI, both located in the northeastern part of the state, are smaller in size and have fewer births than the other four.

TABLE 1: CONDITIONS REPORTED TO THE HRIIS BY HSA OF BIRTH HOSPITAL
HRIIS-1985

	HSA I		HSA II		HSA III		HSA IV		HSA V		HSA VI		Home Birth, Enroute, Out-of-State	
HRIIS Conditions	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total
Birthweight ≤ 2500 gms	491	26.3	391	29.4	151	31.8	1304	33.6	426	39.3	167	23.2	31	39.2
SGA/IUGR	15	0.8	14	1.1	6	1.3	60	1.5	18	1.7	3	0.4	2	2.5
NICU > 24 hrs	816	43.8	294	22.1	57	12.0	1218	31.4	136	12.5	84	11.7	27	34.2
Assisted Ventilation	114	6.1	95	7.1	14	2.9	301	7.8	47	4.3	33	4.6	8	10.1
Seizures	21	1.1	19	1.4	10	2.1	57	1.5	17	1.6	9	1.3	1	1.3
Cerebral Hemorrhage	23	1.2	17	1.3	2	0.4	61	1.6	7	0.6	4	0.5	2	2.5
5 min. Apgar < 5	50	2.7	68	5.1	19	4.0	115	3.0	56	5.2	27	3.8	3	3.4
Congenital Anomalies	127	6.8	165	12.4	52	10.9	226	5.8	224	20.1	124	17.2	2	2.5
Blood Transfusion	14	0.8	13	1.0	3	0.6	26	0.7	4	0.4	1	0.1	1	1.3
Congenital Infection	8	0.4	16	1.2	5	1.1	33	0.9	8	0.8	3	0.4	0	---
Fam. Hx Hearing Loss	150	8.1	222	16.7	141	29.7	397	10.2	120	11.1	228	31.8	2	2.5
Maternal Infection	34	1.8	17	1.3	15	3.2	79	2.0	22	2.0	36	5.0	0	---
TOTAL	1863	100.0	1331	100.0	475	100.0	3877	100.0	1085	100.0	719	100.0	79	100.0

NOTE: The numbers in this table are duplicated counts since more than one HRIIS condition was reported for some infants. 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

Infants Reported to the HRIIS by Birthweight and HSA of Maternal Residence

The high risk condition of low birthweight (≤ 2500 grams) is presented by HSA of maternal residence in Table 2. Analysis of conditions by maternal residence must be interpreted cautiously because maternal residence at the time of conception or during the pregnancy may differ from that reported to HRIIS (residence during the neonatal period).

Completeness of reporting of high risk conditions is a major goal in the first years of the HRIIS. We can estimate how well low birthweight is reported to the HRIIS by comparing the numbers reported via birth certificates to those via the HRIIS. In 1985 there were 4,750 infants with low birthweight according to birth certificates yet only 2,961 infants (62.3%) were reported to HRIIS with low birthweight in 1985.

Infants Reported to the HRIIS by Gestational Age and HSA of Maternal Residence

Gestational age by HSA of maternal residence is presented in Table 3. As we would expect, most infants (61%) were born at a gestational age between 37 and 42 weeks and very few (3%) were born at less than 28 weeks'. The largest number of infants born at a gestational age of under 37 weeks were born to mothers residing in HSA IV (greater Boston).

TABLE 2: INFANTS REPORTED TO THE HRIIS BY BIRTHWEIGHT AND HSA OF MATERNAL RESIDENCE

HRIIS - 1985

BIRTHWEIGHT

HSA	<1500		1500-2500		>2500		Unknown		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
I	83	6.7	434	35.0	723	58.3	0	0	1240	100
II	77	8.3	319	34.6	528	57.2	0	0	923	100
III	56	8.5	254	38.7	345	52.6	1	0	656	100
IV	162	9.8	737	44.6	753	45.6	0	0	1652	100
V	68	6.6	496	47.8	471	45.4	1	0	1037	100
VI	41	6.2	235	35.6	383	58.0	1	0	660	100
*Other	0	0	0	0	2	100.0	0	0	2	100
TOTAL	487	7.9	2475	40.1	3205	51.9	3	0	6170	100

TABLE 3: INFANTS REPORTED TO THE HRIIS BY GESTATIONAL AGE AND HSA OF MATERNAL RESIDENCE

HRIIS - 1985

GESTATIONAL AGE IN WEEKS

HSA	<28		28-32		33-36		37-42		43+		Unknown		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
I	39	3.1	100	8.1	345	27.8	747	60.3	8	1.0	1	0	1240	100
II	28	3.0	100	10.8	180	19.5	592	64.1	18	2.0	5	1	923	100
III	20	3.0	72	11.0	136	20.7	418	63.7	9	1.4	1	0	656	100
IV	46	2.8	201	12.2	474	28.7	913	55.3	13	1.0	5	0	1652	100
V	24	2.3	84	8.1	247	23.8	671	64.8	10	1.0	1	0	1037	100
VI	17	2.6	51	7.7	127	19.2	445	67.4	20	3.0	0	0	660	100
*Other	0	0	0	0	0	0	2	100.0	0	0	0	0	2	100
TOTAL	174	2.8	608	9.9	1509	24.5	3788	61.4	78	1.3	13	0	6170	100

Note: *Other indicates that the maternal residence was unknown.

1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

Gestational age vs. Birthweight by HSA of Maternal Residence

Adequate or normal fetal growth is indicated by comparing birthweight to gestational age. Table 4 indicates that most infants (88%) reported to the HRIIS had an average or above average birthweight for gestational age. The remaining 12% were small for gestational age (birthweight less than tenth percentile for gestational age). Infants who were small for gestational age were reported most from HSAs III (13.9%), HSA IV (12.3%) and HSA V (16.4%).

TABLE 4: GESTATIONAL AGE VS.
BIRTHWEIGHT BY HSA OF MATERNAL RESIDENCE
HRIIS-1985

HSA	Small for gestational age		Average or above-average birth-weight for gestational age		Missing birthweight and/or gestational age		Total	
	No.	%	No.	%	No.	%	No.	%
I	108	8.7	1131	91.3	1	0	1240	100
II	100	10.9	819	89.1	4	0	923	100
III	91	13.9	563	86.1	2	0	656	100
IV	204	12.3	1143	87.6	5	0	1652	100
V	170	16.4	865	83.6	2	0	1037	100
VI	71	10.8	588	89.2	1	0	660	100
*Other	0	0	2	100.0	0	0	2	100
Total	744	12.1	5411	87.7	15	0	6170	100

Note: *Other indicates that the maternal residence was unknown.

1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

IV. TRANSFER AND REFERRAL PATTERNS FOR INFANTS WITH HRIIS CONDITIONS

NICU Transfers Among Infants Reported to the HRIIS by HSA of Birth Hospital

Over 45% of all infants reported to the 1985 HRIIS were transferred to NICUs (Table 5). In Massachusetts, there are a total of eight neonatal intensive care units (NICUs). They are located in the following hospitals: Baystate Medical Center (HSA I), Worcester Memorial (HSA II), Boston City (HSA IV), Brigham and Women's (HSA IV), Children's (HSA IV), Massachusetts General (HSA IV), New England Medical Center (HSA IV), and St. Margaret's (HSA IV).

Some infants born in the southeastern part of the state are transferred for tertiary care to the Women and Infants' Hospital in Providence, Rhode Island. Although this hospital's staff has been oriented to the HRIIS, they are not mandated to report to the HRIIS Massachusetts residents' infants who were born in or transferred to Women and Infants'. Therefore the data for the Southeast portion of the Commonwealth are especially are incomplete and should be interpreted cautiously.

In general, hospitals outside of the Commonwealth do not report Massachusetts residents' infants to the HRIIS. We are currently working to involve these institutions in the HRIIS.

TABLE 5: NICU TRANSFERS AMONG INFANTS REPORTED TO THE HRIIS BY HSA of BIRTH HOSPITAL

HRIIS-1985

HSA	Total Births	No. of Infants Reported to HRIIS	No. of HRIIS NICU Transfers	% of HRIIS Infants to NICU
HSA I	10377	1209	829	68.6
HSA II	9075	852	325	38.1
HSA III	5941	387	61	15.8
HSA IV	33923	2299	1299	56.5
HSA V	11860	814	144	17.7
HSA VI	8536	573	92	16.1
*Other	2064	36	31	86.1
Total births to Massachusetts residents	81776	6170	2781	45.1

Note: *Other indicates that the infant was born at home, enroute or out of state.

1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

Infants Reported to the HRIIS Who Were Transferred Into and Out of NICUs

Among infants reported to the HRIIS who were transferred to NICUs, most (73%) were born at the same hospital. The remaining 27% of infants were born at community hospitals then transported to another hospital for neonatal intensive care. (See Table 6.)

Half the number of HRIIS infants in NICUs were discharged directly to their homes, and another 43% were transferred to either a community hospital or an in-house normal nursery (Table 7). Six percent (166) of the HRIIS infants admitted to NICUs died there. An additional 21 infants died before being transferred to a NICU and 5 infants died after being transferred from NICUs to community hospitals.

The cause of death for infants reported to HRIIS cannot be determined from the HRIIS form alone but the criteria may be related to the underlying causes of death. Among HRIIS infants who died, the most commonly reported conditions reported were: birthweight of $\leq$2500 gms. (73.0%), assisted ventilation for >24 hrs. (40.1%), 5 minute APGAR score of 5 or less (34.3%), congenital anomaly (23.6%) and seizure(s) and/or neurologic abnormality (13.0%).

As reporting to the HRIIS stops at the end of the initial hospitalization, data on the number of infants who expired after discharge to parent or guardian are not available through the HRIIS.

TABLE 6:
INFANTS REPORTED TO THE HRIIS: TYPE OF TRANSFER TO NICU
HRIIS - 1985

Source of Transfer	No.	% of total transfers
Perinatal Center (In-house)	2035	73
Non-Perinatal Center	746	27
TOTAL	2781	100

TABLE 7:
INFANTS REPORTED TO THE HRIIS: TYPE OF TRANSFER OR DISCHARGE FROM NICU
HRIIS - 1985

Type of Transfer or Discharge	No.	% of total transfers
Expired	167	6
Discharged to home	1408	51
Transferred to Community Hospital	664	24
Transferred to in-house normal nursery	542	19
TOTAL	2781	100

Note: 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

Length of Stay in NICU and Non-NICU Settings by HSA

Hospital length of stay varied depending on whether the HRIIS infant was transferred to a NICU. Length of Stay (LOS) for infants who were not transferred to a NICU, those who were, and infants who were transferred from a NICU to a community hospital or in-house normal nursery are presented in Table 8. In each case, the mean length of stay refers to the average of the total number of days spent in a specific hospital setting. The NICU length of stay refers to the total LOS in a NICU setting which can be within one or more NICUs.

Among infants reported to the HRIIS who were not transferred to a NICU, the mean length of stay was 5.1 days. The median LOS for these infants was 3 days. By HSA of birth hospital, the shortest mean length of stay was for HSA I (3.8) and the longest was for the "Other" category (7.6). Some of the infants represented in this category were born under unusual or uncertain circumstances (such as in a car, or at home with unexpected complications) and therefore perhaps required a longer hospitalization. This category also includes infants born out-of-state.

HRIIS infants who were transferred to a NICU had a longer mean length of stay than infants who remained in a non-NICU setting. The overall mean length of stay in a NICU was 17.5 days, more than three times as long as for infants who were not transferred to a NICU. The median LOS for these infants was 7 days. Infants born in HSA I, II, and IV had long lengths of stay, as we would expect, since these are the areas where the eight NICUs are located. Infants in the "Other" category for HSA had the longest mean LOS in a NICU (26.7 days).

The mean length of stay among HRIIS infants back-transferred from NICUs to community hospitals or in-house normal nurseries was 10.8. These infants had a median length of stay of 6 days. Infants born in HSA I had the shortest LOS (6.3 days) and infants in the "Other" category for HSA had the longest LOS (19.8 days).

TABLE 8: MEAN LENGTH OF STAY (LOS) IN NICU AND NON-NICU SETTINGS
By HSA of Birth Hospital

	Length of Stay (days) for Infants Not Transferred to NICU			Length of Stay (days) in a NICU			Length of Stay (days) in Community Hospital/ Normal Nursery (after discharge from NICU)		
HSA	# of infants	Sum of Hospital days	Mean LOS	# of infants transferred to NICU	Sum of NICU days	Mean LOS	# of infants transferred to CH/NN	Sum of Hospital days	Mean LOS
1	380	1460	3.8	829	12483	15.1	206	1296	6.3
2	527	2371	4.5	325	7043	21.7	126	2066	16.4
3	326	1647	5.1	61	810	13.3	34	536	15.8
4	1000	5963	6.0	1299	24035	18.5	733	7659	10.4
5	670	3644	5.4	144	2121	14.7	55	752	13.7
6	481	2263	4.7	92	1313	14.3	33	314	9.5
*Other	5	38	7.6	31	829	26.7	19	376	19.8
TOTAL	3389	17386	5.1	2781	48634	17.5	1206	12999	10.8

Note: *Other indicates that the infant was born at home, enroute or out of state.

1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

Infants Reported to the HRIIS who Were Referred for Follow-up Care by HSA of Maternal Residence

Referrals to community-based services such as an Early Intervention Program (EI) or Visiting Nurse Association (VNA) are made by health care personnel prior to discharge from the hospital. Twenty-five percent of HRIIS infants were referred to follow-up services. Referrals for many infants are made after hospital discharge, at the parents' request or by the infant's physician. Because HRIIS does not collect information after discharge, the number of referrals in Table 9 is not representative of all referrals for high risk infants. Among HRIIS infants referred for follow-up services, 3% of HRIIS infants were referred for EI programs, 20% to VNA or Public Health Nursing services, and another 8% for other medical or social services (such as surgery, WIC, or DSS).

TABLE 9: INFANTS REPORTED TO THE HRIIS WHO WERE REFERRED FOR FOLLOW-UP CARE BY HSA OF MATERNAL RESIDENCE
HRIIS - 1985

HSA	No. HRIIS Infants	Early Intervention		VNA and/or PHN		Other Medical or Social Service Referral	
		No.	%	No.	%	No.	%
I	1240	75	6.0	333	26.9	47	3.8
II	923	17	1.8	193	20.1	84	9.1
III	656	13	2.0	35	5.3	40	6.1
IV	1652	66	4.0	221	13.4	141	8.5
V	1037	24	2.3	376	36.2	106	10.2
VI	660	3	0	60	9.1	49	7.4
*Other	2	0	0	1	0	0	0
TOTALS	6170	198	3.2	1219	19.8	467	7.6

Note: *Other indicates that the maternal residence was unknown.

1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

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[illegible]

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V. SPECIAL REPORT: The Hearing Evaluation Program for Infants and Toddlers

Overview

Massachusetts was the first state to enact legislation (Ch. 1095, Acts of 1971) mandating a system for the early identification of infants and toddlers at risk for hearing impairment. The Hearing Evaluation Program for Infants and Toddlers is designed to:

- @ Identify infants and young children at risk for hearing impairment.
- @ Inform parents generally about the importance of the sense of hearing to an infant's development and specifically about the risk status of their newborn.
- @ Provide access to specialized audiological evaluations to at-risk infants by serving as a payor of last resort.

The Joint Committee on Infant Hearing, with representatives of the American Academy of Pediatrics (AAP), American Nurses Association (ANA), American Speech-Language-Hearing Association (ASHA) and the American Academy of Ophthalmology and Otolaryngology, advocate the Risk Register method of identification of infants at risk for hearing impairment. The Risk Register, a listing of categories of risk factors known to be associated with hearing loss in the infant, is a more feasible and cost-effective approach than mass behavioral screening.

The following eight risk factors were selected to identify infants and toddlers at risk for hearing impairment in Massachusetts. All of these items are reported on the 1985 HRIIS form.

1 Family member with a hearing loss since childhood

2 Mother had German measles, cytomegalovirus, toxoplasmosis or genital herpes during pregnancy

3 Birthweight of 1800 grams (4 lbs.) or less

4 Meningitis or any congenital infection.

5 Assisted ventilation for 24 hours or more.

6 Exchange blood transfusion for severe jaundice

7 Apgar score of 5 or less at five minutes

8 Congenital anomaly(ies) involving the ears, head, neck, eyes for example, cleft lip/palate, Down syndrome.

Although most of the program's activities operate through the HRIIS, services are not limited to the HRIIS population. Any child whose health history includes one or more of the risk factors may be registered at any time before the third birthday. A child may be eligible for the HEP but

not be a part of the HRIIS. For instance, a risk factor may be diagnosed after the child leaves the hospital, or there may be incomplete information provided by the parents at the time of delivery or incomplete reporting to the HRIIS by the hospital.

Ensuring that children are referred to the Hearing Evaluation Program for appropriate audiological evaluations for which they are eligible depends upon informed and knowledgeable health care providers in primary care, Early Intervention Programs, Community Nursing Agencies and Infant Follow-Up Programs.

The Department of Public Health's commitment to this program is based on the recognition that hearing has a very significant role in the child's development and that a hearing impairment may be a "hidden handicap." Identification during the first years of life provides the greatest opportunity to intervene during the critical period for speech and language development. Failure to compensate for hearing impairment by otological, audiological and/or educational actions is likely to have an adverse effect on the child's emotional, social and intellectual development.

Hospitals with maternity and newborn services are mandated to:

@ Provide all parents with information describing the Hearing Evaluation Program for Infants and Toddlers.

@ Report every infant at risk for hearing impairment through the HRIIS. The report from the hospital is used as the basis for the Parent Outreach letter (see Appendix G) which is mailed to the family of every infant identified as being at risk, to ensure that parents are aware of the risk status of the infant and to encourage registration of the infant with the Hearing Evaluation Program.

Massachusetts residents are eligible for the program from birth until three years of age, if they have one or more of the eight risk factors. Registration during infancy is encouraged and is important for early detection and intervention. As soon as any one of the eight risk factors associated with hearing loss is detected among children ages 0 to 3 years, anyone - including parents, audiologists, nurses, doctors or others caring for young children - may telephone and register the child with the Hearing Evaluation Program. There are six intake points across the state for registering children with the Program. These intake points are located in Boston and Regional Public Health Offices in the Northeast, Southeast, Barnstable county, Central and Western parts of the state.

Once infants are registered, hearing evaluations are provided at any one of the 26 audiological centers throughout the state approved by the MDPH to provide appropriate tests to infants and young children. Parents are offered a choice among the approved facilities. There are no direct costs to the family once a child is registered with the Department until a diagnosis is established or the child reaches the third birthday. Any insurance or Medicaid available to the family will be billed. However, if rejected or only partly paid by the insuror, the MDPH will assume responsibility for payment.

Data Description

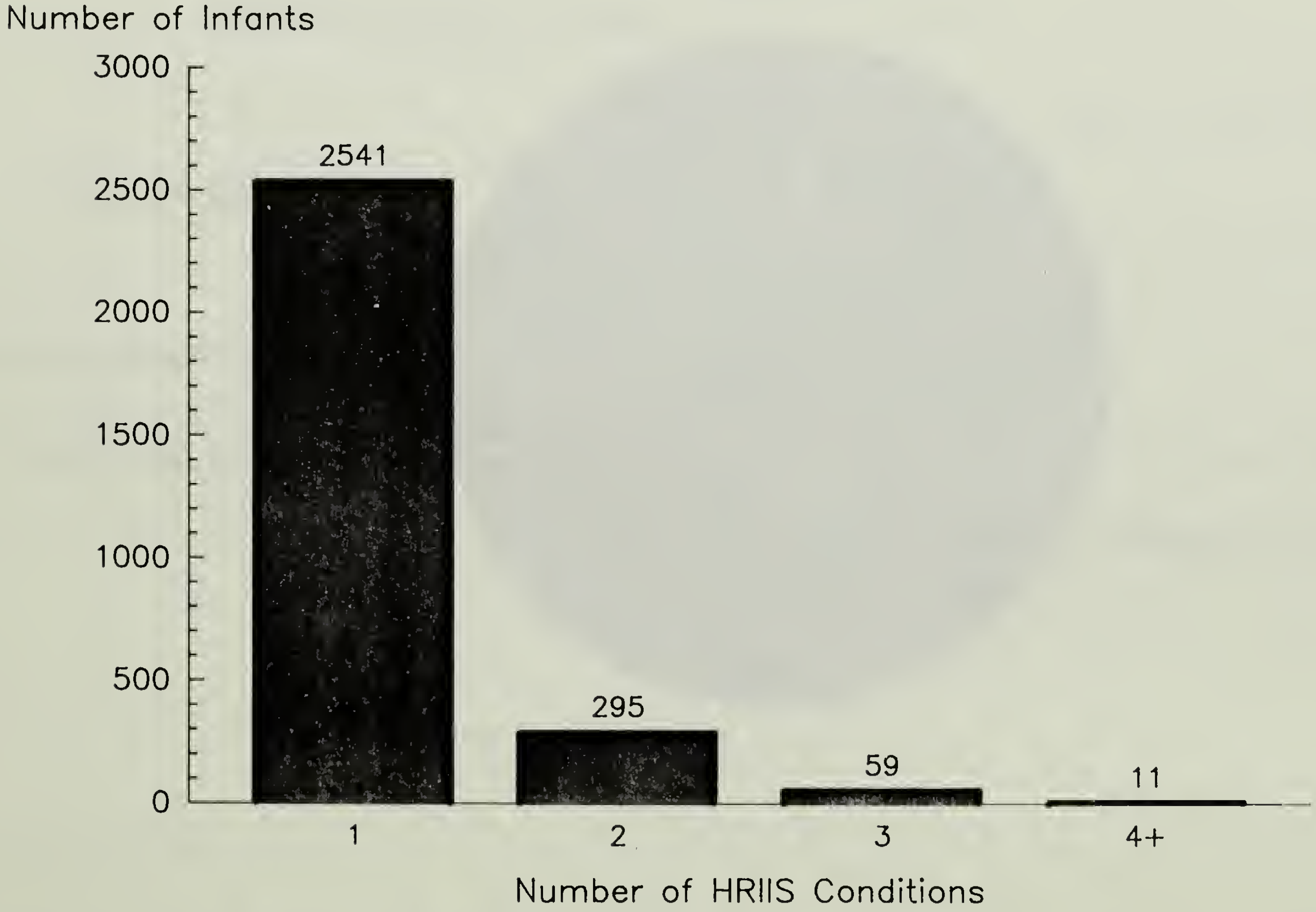
In 1985, 2906 infants at risk for hearing loss were reported to the HRIIS. Of these infants, 2541 had just one of the eight HRIIS criteria selected to identify infants and toddlers at risk for hearing impairment in Massachusetts; 295 had two criteria, 59 had three, and 11 had four or more. The most commonly reported high risk conditions among the selected eight, were: family history of hearing loss (37%), birthweight less than or equal to 1800 gms (23%) and assisted ventilation (16%).

Table 10 lists the conditions reported for infants at risk for hearing loss by HSA of birth hospital.

Graph 3

Infants Reported to the HRIIS at Risk for Hearing Loss with one or more HRIIS Condition

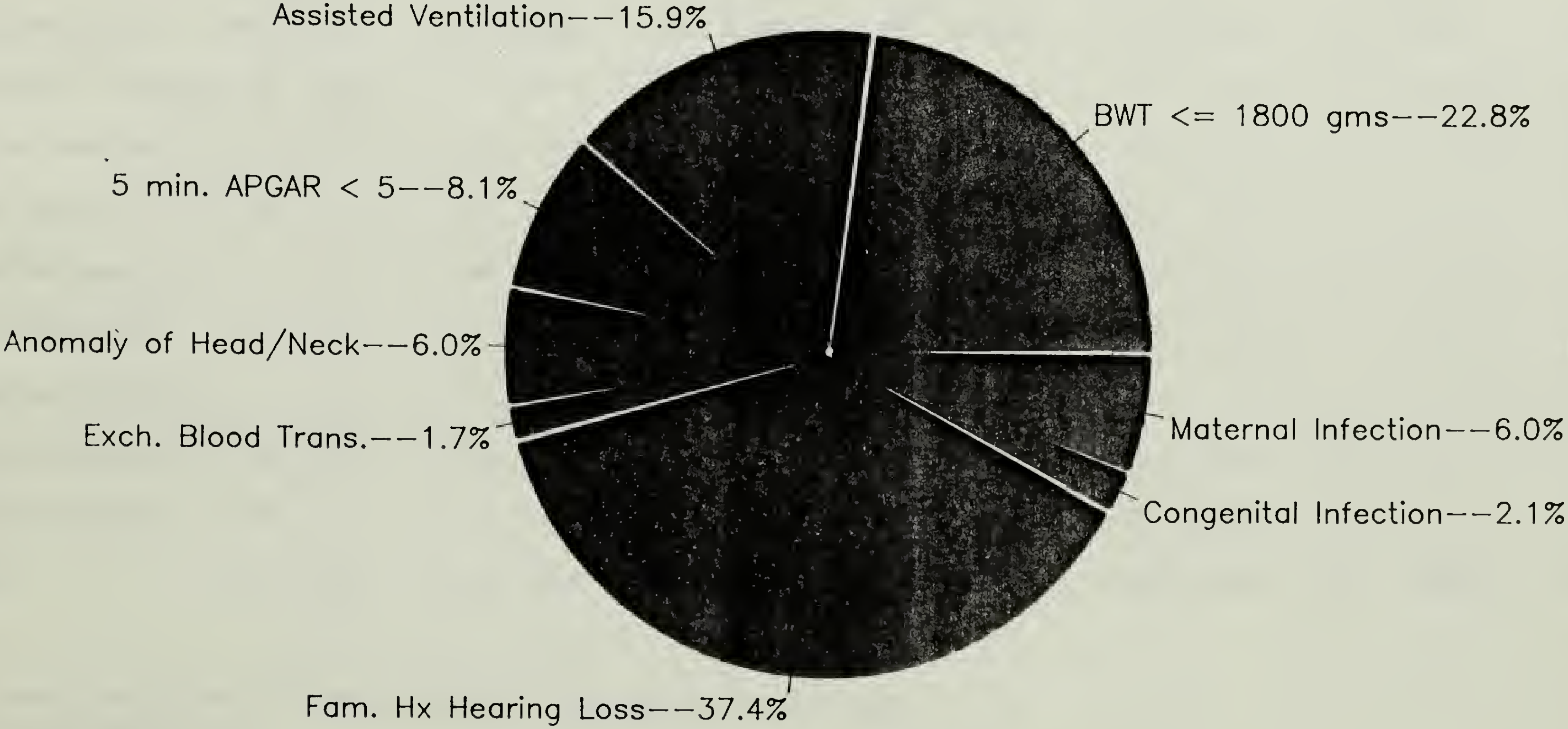
HRIIS-1985



Data Source : Division of Family Health Services, DPH

Note : One or more of eight HRIIS conditions places infants at risk for hearing loss (see text)

Graph 4
Percent of Conditions Reported to the HRIIS for Infants at Risk for Hearing Loss
HRIIS - 1985



Data Source : Division of Family Health
Services, DPH

Note : N=3367. This is a duplicated count. More than one HRIIS condition was reported for some infants.

TABLE 10: CONDITIONS REPORTED TO THE HRIIS FOR INFANTS AT RISK FOR HEARING LOSS BY HSA OF BIRTH HOSPITAL HRIIS-1985

	HSA I		HSA II		HSA III		HSA IV		HSA V		HSA VI		*Other	
HRIIS Conditions	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total	No.	% Total
Birthweight ≤ 1800 gms	104	22.4	111	20.3	18	8.0	441	31.5	59	17.2	18	5.0	18	60.0
Assisted Ventilation	97	21.0	82	15.0	13	5.8	271	19.3	37	10.8	27	7.6	8	26.7
5 min. Apgar < 5	39	8.4	53	9.7	13	5.8	102	7.3	45	13.1	19	5.3	1	3.3
Congenital Anomalies**	21	4.5	36	6.6	18	8.0	53	3.8	48	14.0	25	7.0	0	---
Blood Transfusion	13	2.8	11	2.0	3	1.3	25	1.8	4	1.2	1	0.3	1	3.3
Congenital Infection	7	1.5	15	2.7	5	2.2	33	2.4	8	2.4	3	0.8	0	—
Fam. Hx Hearing Loss	149	32.1	222	40.1	141	62.4	397	28.3	120	35.0	228	64.1	2	6.7
Maternal Infection	34	7.3	16	2.9	15	6.7	79	5.7	22	6.4	36	10.1	0	---
TOTAL	464	100.0	546	100.0	226	100.0	1401	100.0	343	100.0	357	100.0	30	100.0

*Other indicates that the infant was born at home, enroute or out-of-state.
**Of the head or neck.

NOTE: The numbers in this table are duplicated counts since more than one HRIIS condition was reported for some infants. 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, DPH
PREPARED BY: Division of Family Health Services, DPH

VI. SPECIAL REPORT: Congenital Anomalies

Overview

Congenital anomalies or birth defects are a leading cause of infant mortality and lifelong disability. Over 20% of deaths occurring before the first birthday are due to congenital anomalies. Those children who survive often require specialized medical and educational services.

The causes of at least 60% of all congenital anomalies are unknown. A major goal of birth defects surveillance is to monitor the occurrence of all cases of particular conditions over time to more efficiently detect changes in prevalence. Specific health habits and exposures that may affect pregnancy can then be evaluated through epidemiologic studies.

Since the thalidomide tragedy in 1959-61, there has been an increasing interest in birth defects monitoring as a means of early warning for health hazards. The Centers for Disease Control (CDC) started the Metropolitan Atlanta Congenital Defects Program (MACDP) in 1967 and the Birth Defects Monitoring Program (BDMP) in 1974. The latter is the first nationwide monitoring system established in the United States. The BDMP obtains discharge diagnoses on approximately one million live and stillborn infants per year from hospitals that subscribe to the Commission on Professional and Hospital Activities (CPHA) for data processing. Hospital admissions up to four days of life are included. Births in the northeast census region of the country comprise about 16% of all births included in the BDMP. Six Massachusetts hospitals are represented in the sample, with approximately 5,000 births.

The International Clearinghouse for Birth Defects Monitoring Programs, originally sponsored by the March of Dimes Birth Defects Foundation, was established in 1974 so that countries could share information about the prevalence of particular congenital anomalies and suspected teratogens. The Clearinghouse is currently partially supported by the March of Dimes and is now associated with the World Health Organization.

These programs have been the models used by state health departments in their efforts to develop systems for birth defects surveillance. Thirty-seven states are presently operating or developing an adverse reproductive outcome surveillance system that includes birth defects monitoring.

Data from the CDC indicate that birth defects are diagnosed during the newborn period in approximately 3% of live births. In Massachusetts, we do not yet have an accurate picture of how many infants are born with congenital anomalies. The initial goal of congenital anomaly monitoring through the High Risk Infant Identification System (HRIIS) is to determine the baseline occurrence of congenital anomalies among newborns in the Commonwealth. This will allow the MDPH to better address questions posed by citizens and health professionals about the frequency of these conditions.

It is required by law that all newborns with a congenital anomaly known or suspected prior to the time of discharge from the hospital be reported to the HRIIS.

Data Description

In 1985, 794 infants with congenital anomalies were reported to the HRIIS. Of these 794 infants, 691 had one anomaly, 80 had two, and 23 had three, for a total of 920 reported anomalies.

Graph 5 shows prevalence rates of certain congenital anomalies reported to the HRIIS and those from the CDC Birth Defects Monitoring Program. The BDMP includes cases of congenital anomalies identified in stillbirths, whereas the HRIIS does not. However, these sources are similar in that they ascertain cases diagnosed up until neonatal discharge from the hospital. These specific anomalies are often singled out for monitoring purposes because they are more prevalent than most others and are usually identifiable at birth. Although regional differences in congenital anomaly rates between Massachusetts and the country as a whole are expected, the vast differences between the two indicate either that Massachusetts has a much lower occurrence of these anomalies, or more likely, that congenital anomalies in the Commonwealth are underreported to the HRIIS. This comparison is a useful way to estimate the extent to which specific anomalies were underreported to the HRIIS in 1985. Anomalies that were reported best include cleft lip with or without cleft palate, limb reductions and Down syndrome. The most severely underreported congenital anomaly was anencephaly. One possible explanation for this disparity is that many fetuses with anencephaly are stillborn, while only livebirths are reported to the HRIIS. Hip dislocation, hydrocephalus and hypospadias were also greatly underreported to the HRIIS in 1985.

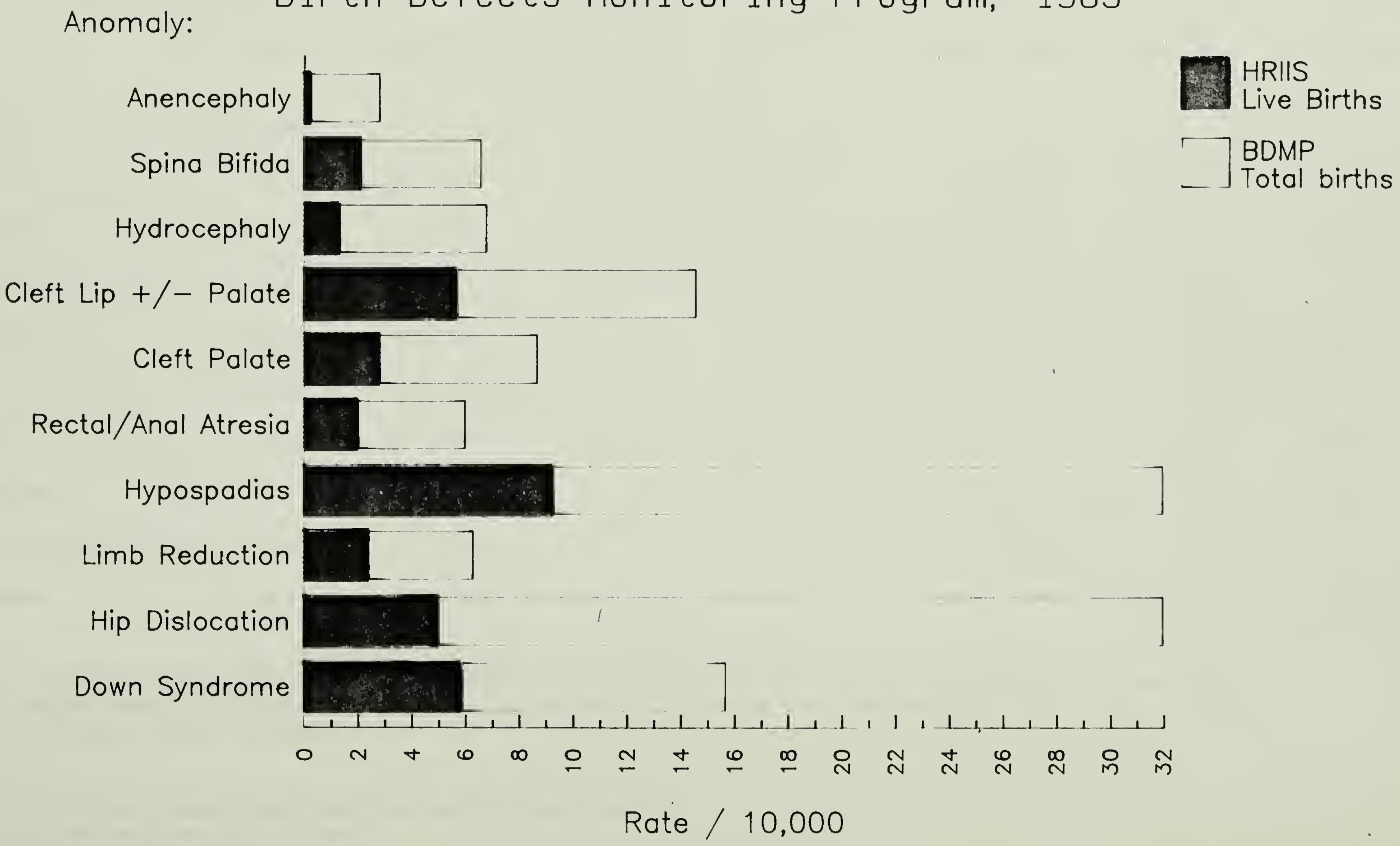
Table 11 shows prevalence rates for certain congenital anomalies reported to the HRIIS by HSA of maternal residence. Prevalence rates are lower than expected for most congenital anomalies in most regions as compared to national rates from the BDMP (graph 5). These rates do not reflect the true distribution of congenital anomalies in Massachusetts, however, because many affected infants were not reported to the HRIIS in the first full year of data collection. Differences in rates of particular anomalies across regions are likely to be due to variations in reporting practices rather than true disparities in the occurrence of congenital anomalies in different parts of the state.

Premature infants (<38 wks) have higher rates of congenital anomalies than do full-term infants (38-42 wks) in all categories except ear, face and neck and integument (Table 12). Post-mature infants (>42 wks) have higher rates of anomalies involving the nervous system than do infants of 38-42 weeks gestation. These trends must be interpreted cautiously since underreporting can alter them considerably. In addition, some post-mature infants were undoubtedly born to mothers with insulin-dependent diabetes mellitus.

As seen in Table 13, low birthweight infants (1500-2500 gms.) have higher rates of congenital anomalies than do normal birthweight infants (>2500 gms). Very low birthweight infants (<1500 gms) appear to have higher rates of congenital anomalies involving the nervous system, circulatory system and respiratory system than do low or normal birthweight infants. These relationships should be interpreted with caution, however, because a comparison of trends in congenital anomaly

rates by birthweight assumes that reporting was equally complete for all anomaly and birthweight categories. Data from the Collaborative Perinatal Project, a prospective study of over 50,000 pregnancies, suggests that a similar trend exists for other categories of congenital anomalies as well, such that prevalence rates of all anomalies increase as birthweight decreases. A recent analysis of data on white singleton live births in the Metropolitan Atlanta Congenital Defects Program further corroborates this trend.

Graph 5
Prevalence of Specific Congenital Anomalies Reported to the HRIIS & to the CDC - Birth Defects Monitoring Program, 1985



Data Source: Divisions of Family Health Services and Health Statistics & Research, DPH
Centers for Disease Control (CDC), Atlanta, GA

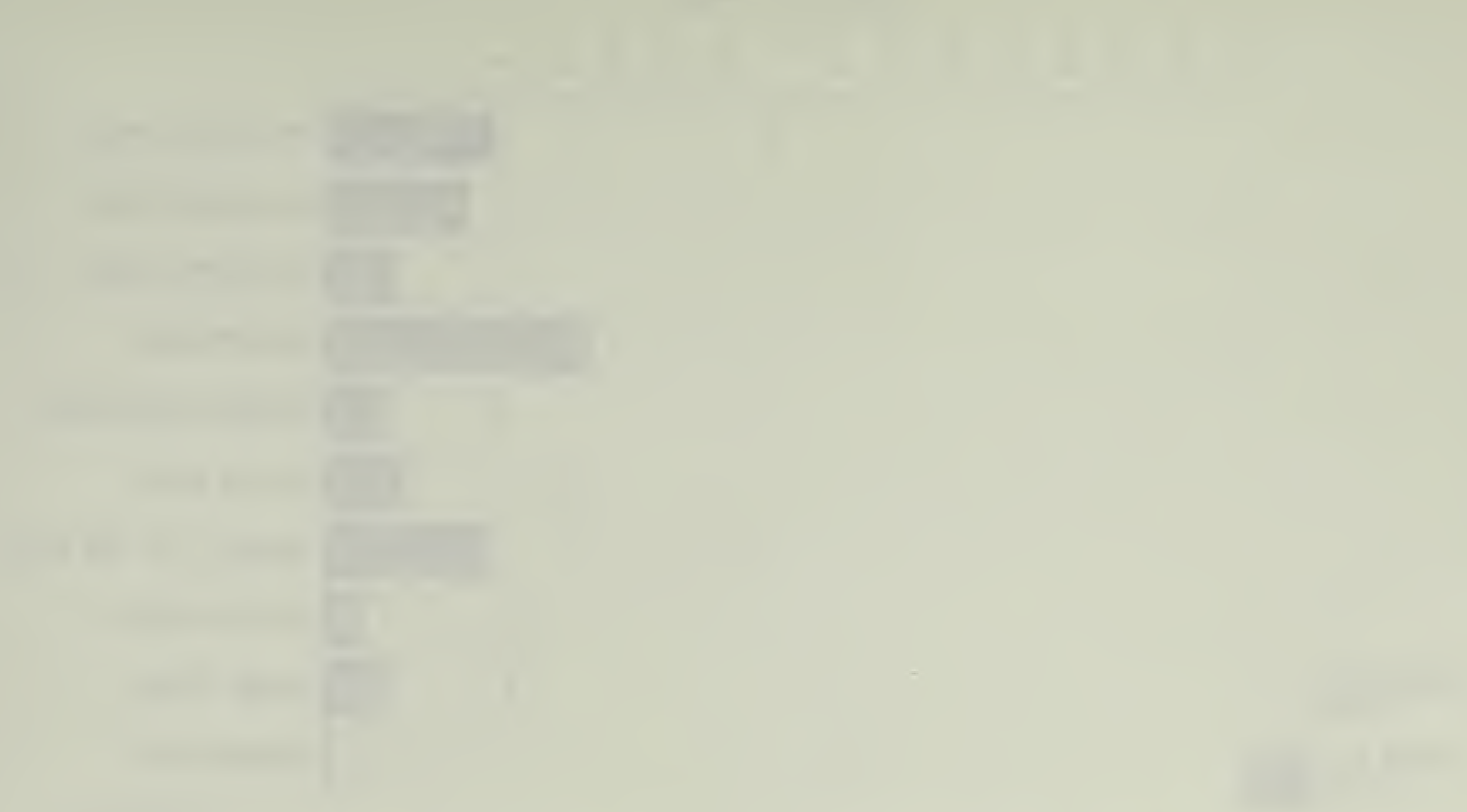


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TABLE 11: PREVALENCE OF SPECIFIC CONGENITAL ANOMALIES REPORTED TO THE HRIIS BY HSA OF MATERNAL RESIDENCE
HRIIS-1985
Rates per 10,000 Resident Live Births

	HSA I		HSA II		HSA III		HSA IV		HSA V		HSA VI		State Total	
Total Number of Live Births In each HSA	10,733		10,654		8,336		28,197		15,215		8,641		81,776	
Anomaly	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Anencephaly	1	0.9	0	---	0	---	1	0.4	0	---	0	---	2	0.2
Spina Bifida	4	3.7	5	4.7	2	2.4	2	0.7	3	2.0	1	1.2	17	2.1
Hydrocephaly	1	0.9	1	0.9	1	1.2	4	1.4	1	0.7	3	3.5	11	1.3
Cleft Lip +/- Cleft Palate	8	7.5	9	8.4	4	4.8	6	2.1	16	10.5	4	4.6	47	5.7
Cleft Palate	5	4.6	6	5.6	2	2.4	3	1.1	5	3.3	2	2.3	23	2.8
Rectal/Anal Atresia	1	0.9	2	1.9	2	2.4	5	1.8	4	2.6	3	3.5	17	2.1
Hypospadias	10	9.3	18	16.9	8	9.6	7	2.5	22	14.5	11	12.7	76	9.3
Limb Reduction	3	2.8	5	4.7	0	---	8	2.8	2	1.3	2	2.3	20	2.4
Congenital Hip Dislocation	6	5.6	4	3.8	1	1.2	8	2.8	7	4.6	15	17.4	41	5.0
Down Syndrome	5	4.6	6	5.6	7	8.4	12	4.3	12	7.9	6	6.9	48	5.9

NOTE: The numbers in this table are duplicated counts since more than one congenital anomaly was reported for some infants. 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, and Division of Health Statistics and Research, DPH
PREPARED BY: Division of Family Health Services, DPH

TABLE 12: PREVALENCE OF CONGENITAL ANOMALIES REPORTED TO THE HRIIS BY GESTATIONAL AGE; HRIIS-1985

Rates per 10,000 Resident Live Births

	Gestational Age							
	<38 wks		38-42 wks		>42 wks		Total	
Total Number of Births	8,652		64,174		7,738		81,776*	
Anomaly Group	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Anencephaly	1	1.2	1	0.2	0	----	2	0.2
Spina Bifida	4	4.6	13	2.0	0	---	17	2.1
Other Cong. Anoms. of Nervous System	9	10.4	7	1.1	3	3.9	19	2.3
Cong. Anoms. of Eye	2	2.3	14	2.2	0	----	16	2.0
Cong. Anoms. of Ear, Face, & Neck	4	4.6	34	5.3	0	----	38	4.6
Bulbus Cordis Anoms. & Anoms. of Cardiac Septal Closure	2	2.3	14	2.2	0	----	16	2.0
Other Cong. Anoms. of Heart	14	16.2	51	7.9	2	2.6	67	8.2
Other Cong. Anoms. of Circulatory System	14	16.2	13	2.0	0	----	27	3.3
Cong. Anoms. of Respiratory System	4	4.6	9	1.4	1	1.3	14	1.7
Cleft Palate/Cleft Lip	11	12.7	57	8.9	2	2.6	70	8.6
Other Cong. Anoms. of Upper Alimentary Tract	11	12.7	14	2.2	0	---	25	3.1
Other Cong. Anoms. of Digestive System	10	11.6	22	3.4	0	----	32	3.9
Cong. Anoms. of Genital Organs	13	15.0	83	12.9	3	3.9	99	12.1
Cong. Anoms. of Urinary System	10	11.6	21	3.3	0	----	31	3.8
Certain Cong. Musculoskeletal Deformities	13	15.0	89	13.9	0	----	102	12.5
Other Cong. Anoms. of Limbs	21	24.3	80	12.5	4	5.2	105	12.8
Other Cong. Musculoskeletal Anoms.	11	12.7	42	6.5	0	----	53	6.5
Cong. Anoms. of the Integument	6	6.9	53	8.3	1	1.3	60	7.3
Chromosomal Anoms.	17	19.6	46	7.2	0	---	64*	7.8
Other Anoms.	5	4.6	8	1.2	0	----	13	1.6
Cong. Anoms. Outside ICD-9-CM 740-759	9	10.4	40	6.2	1	1.3	50	6.1
Total Anomalies	191	220.8	711	110.8	17	22.0	920*	112.5

* Includes infants of unknown gestational age

NOTE: The numbers in this table are of anomalies, not infants since more than one congenital anomaly was reported for some infants 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, and Division of Health Statistics and Research, DPH
PREPARED BY: Division of Family Health Services, DPH

TABLE 13: PREVALENCE OF CONGENITAL ANOMALIES REPORTED TO THE HRIIS BY BIRTHWEIGHT; HRIIS-1985

Rates per 10,000 Resident Live Births

	Birthweight							
	<1500 gms		1500-2500 gms		>2500 gms		Total	
Total Number of Births	844		3,906		76,954		81,776*	
Anomaly Group	No.	Rate	No.	Rate	No.	Rate	No.	Rate
Anencephaly	0	----	2	5.1	0	----	2	0.2
Spina Bifida	1	11.8	0	----	16	2.1	17	2.1
Other Cong. Anoms. of Nervous System	3	35.5	4	10.2	12	1.6	19	2.3
Cong. Anoms. of Eye	1	11.8	0	----	15	1.9	16	2.0
Cong. Anoms. of Ear, Face, & Neck	0	----	4	10.2	34	4.4	38	4.6
Bulbus Cordis Anoms. & Anoms. of Cardiac Septal Closure	1	11.8	2	5.1	13	1.7	16	2.0
Other Cong. Anoms. of Heart	1	11.8	9	23.0	56	7.3	67*	8.2
Other Cong. Anoms. of Circulatory System	9	106.6	5	12.8	13	1.7	27	3.3
Cong. Anoms. of Respiratory System	2	23.7	1	2.6	11	1.4	14	1.7
Cleft Palate/Cleft Lip	1	11.8	6	15.4	63	8.2	70	8.6
Other Cong. Anoms. of Upper Alimentary Tract	1	11.8	9	23.0	15	1.9	25	3.1
Other Cong. Anoms. of Digestive System	1	11.8	6	15.4	25	3.2	32	3.9
Cong. Anoms. of Genital Organs	1	11.8	6	15.4	92	12.0	99	12.1
Cong. Anoms. of Urinary System	0	----	6	15.4	25	3.2	31	3.8
Certain Cong. Musculoskeletal Deformities	2	23.7	10	25.6	90	11.7	102	12.5
Other Cong. Anoms. of Limbs	3	35.5	14	35.8	88	11.4	105	12.8
Other Cong. Musculoskeletal Anoms.	2	23.7	10	25.6	40	5.2	53*	6.5
Cong. Anoms. of the Integument	0	----	3	7.7	57	7.4	60	7.3
Chromosomal Anoms.	3	35.5	15	38.4	46	6.0	64	7.8
Other Anoms.	0	----	3	7.7	10	1.3	13	1.6
Cong. Anoms. Outside ICD-9-CM 740-759	1	11.8	5	12.8	44	5.7	50	6.1
Total Anomalies	33	391.0	120	307.2	765	99.4	920*	112.5

* Includes infants of unknown birthweight.

NOTE: The numbers in this table are of anomalies, not ifants since more than one congenital anomaly was reported for some infants. 1985 was the first full year of data collection for the HRIIS. Because the system was still in its initial stages, data inferences should be limited.

DATA SOURCE: Division of Family Health Services, and Division of Health Statistics and Research, DPH
PREPARED BY: Division of Family Health Services, DPH

Plans for a Congenital Anomaly Surveillance System:

The Department of Public Health has plans to establish a Congenital Anomaly Surveillance System based on data obtained from the HRIIS and birth certificates. This system, coordinated by the Massachusetts Genetics Program, within the Perinatal and Genetics Unit, will be used to identify trends in the frequency of birth defects over time and in different communities, to facilitate research into the possible existence of new teratogens or increased exposure to old ones, and to assist public health planning of genetic services for the early detection, treatment, and possible prevention of birth defects.

Monitoring the occurrence of congenital anomalies requires precise and complete reporting of all affected infants. The Department of Public Health awarded contracts to Massachusetts neonatal intensive care units beginning in July 1987 for the development of two projects designed, in part, to encourage accurate and complete reporting of infants with congenital anomalies. The first is a Regional Enhancement Program for the development of outreach methods to provide education, technical assistance and consultation to service providers in community hospitals and agencies around perinatal and high risk issues including congenital anomalies. The second is a Collaborative Perinatal System for the establishment of a minimum NICU data set that integrates data required by the HRIIS and ensures that HRIIS data is reported in an accurate and timely manner to the MDPH, with particular attention to the reporting of congenital anomalies.

Continued cooperative efforts between the Department of Public Health and health care providers are necessary to better serve children with birth defects and their families. The Congenital Anomaly Surveillance System and initiatives to improve reporting, will help us to develop a closer working relationship with hospital staff who provide care for infants with congenital anomalies. It is the Department's goal for this system to be operational in 1988.

References

Edmonds LD, Layde PM, James LM, et al: Congenital Malformations Surveillance: Two American Systems. Int. J. Epid. 10(3): 247-252, 1981.

Flynt JW, Norris LK, Zaro S, et al: State Surveillance of Birth Defects and Other Adverse Reproductive Effects. U.S. Department of Health and Human Services, April 1987.

Guyer B, Brown L, Evans F (eds): The Health of Women and Children in Massachusetts, a Source Book of Data. Department of Public Health, Division of Family Health Services, 1985.

Heinonen OP, Slone D, Shapiro S: Birth Defects and Drugs in Pregnancy. Massachusetts, John Wright, 1983.

Oakley GP, Erickson JD, McCarthy BJ, et al: Low-Birthweight Prevention: The need for a first trimester agenda. Presented at the annual meeting of the American Epidemiological Society, Los Angeles, CA, March 21, 1986.

VII. QUALITY ASSURANCE

The process of capturing the information on the HRIIS reporting form is complicated by many factors. The form may not accompany the infant to the tertiary center if the transfer is made quickly or if multiple transfers are made. The tertiary center may not send the form back to the community hospital. Discharge and referral information may be missed because the hospital department responsible for discharge planning may not have direct contact with the nursing staff responsible for completing the form. This referral information may be available at a location in a hospital other than the primary site of the infant's care. Hospitals are responsible for assuring that the form is completed, but in the absence of a well-organized process in each hospital, data may be lost or its recording delayed.

The HRIIS has the following quality assurance goals:

@ to revise the HRIIS reporting form with more clearly defined criteria for conditions that have been previously underreported and/or misinterpreted;

@ to refine protocols for collecting and processing data;

@ to provide more comprehensive training, information, and assistance to hospital staff involved with the reporting of high risk infants; and

@ to determine the accuracy and completeness of reporting for certain high risk criteria.

A. Form Revision

Appendix B of this report includes copies of the 1985 and 1987 High Risk data collection forms. Both forms contain demographic information (first and last name of both infant and mother, address, hospital of birth), infant characteristics at birth and during the initial hospitalization, attributes of the infant (birthweight, gestational age, high risk condition), and discharge and referral information (transfer to NICU, infant living or expired, back transfer to community hospital, primary care provider, follow-up referrals and discharge dates). There is also a question relating to infants who were not discharged to their parents. This indicates those situations where it is inappropriate to contact parents for follow-up referrals for hearing evaluation.

The twelve HRIIS criteria were selected as risk factors for developmental, neurological and physical dysfunction in the infant. Some of the HRIIS data can also be found on the birth certificate. For instance, infants with low birthweight, low APGAR scores and congenital anomalies can be identified from both sources of data. However, the HRIIS data can provide more comprehensive infant information than birth certificates. For example, birth certificates are completed very soon after birth when some conditions such as congenital anomalies may not be fully diagnosed. The HRIIS form "follows" the infant throughout the initial hospitalization, which allows a longer period for detecting high risk conditions. Also, birth certificates are, in general, completed by obstetrical personnel and HRIIS forms are filled out by neonatal or pediatric staff.

The HRIIS is evolving and some of the information collected in 1985 is not as useful as initially anticipated, while other potentially useful data are missing. Accordingly, a new form has been designed and was be implemented in July 1987. The form changes are listed below:

- Complete address of mother in computer-entry format (to more specifically determine the geographic patterns in reporting high risk conditions and to facilitate producing address lists for notifying parents of children at risk for hearing loss).

- Source of payment for child's hospitalization costs has been added to allow an analysis of the distribution of high risk conditions by payment source. From this it should be possible to identify financial resources available for payment.

- The standard definition for severe growth retardation (birthweight less than the tenth percentile for gestational age) was added to the form.

- The minimum length of time in a NICU required (before an infant is considered at risk for increased morbidity and mortality) was changed from 24 to 48 hours to avoid identifying infants who are admitted for observation and are not truly at risk. In addition, space for specifying reasons for NICU admission has been provided.

- The criterion of seizures and/or other neurologic abnormalities was separated into two: one for seizures and another for other neurologic abnormalities, to provide more specific information.

- The congenital infection criterion was reworded to include: rubella, toxoplasmosis, cytomegalovirus, genital herpes, syphilis, meningitis and other. This will yield more specific data on infections.

- The congenital anomaly coding has been expanded to incorporate two additional characters. These characters will help to provide more detail for data analysis. For example, the additional codes will specify bilateral or unilateral conditions and indicate more precisely the location of particular anomalies. This coding convention is a system created by Centers for Disease Control (CDC), and its use will make our data more comparable to data from the CDC.

- Medical record numbers for the birth hospital, NICU, and community hospital have been added to facilitate the completion of missing information.

- Mother's telephone number has been deleted.

There are some limitations to the data set that remains, even with these new extensions. In particular, no practical way was found to track transfers from one NICU to another, so that NICU lengths of stay could be individually calculated. However, the expanded data base is expected to be a valuable complement to existing data within the department such as vital statistics.

B: Collecting and Processing Data

Completed forms are forwarded to MDPH where they are evaluated for completeness. Hospitals are telephoned and asked to provide missing information which is then entered on the form. The regional nurses also receive copies of the forms with the missing information for follow-up. The original forms are filed until completed.

The completed forms are entered into a computer file and checked for data entry errors. Until all applicable information on the form has been completed, the forms are kept in a "pending" file. Statistics generated from the system are preliminary until pending forms are completed for a particular time period.

C: Ongoing Training and Reporting

Review of the data collection process illustrates the need for cooperation and coordination among birth hospitals and NICUs. This requires training of hospital staff and technical assistance by perinatal nurse coordinators, supplemented with central office staff as appropriate. The Perinatal Nurse Coordinators are the primary links between the HRIIS and the birth hospitals and NICUs in their respective regions. By maintaining frequent communication with hospital personnel, including discharge planning staff, the nurses assure complete and timely reporting, and promote appropriate referrals of high risk infants.

The Department of Public Health awarded contracts to Massachusetts neonatal intensive care units beginning in July 1987 for the development of two projects designed, in part, to encourage accurate and complete reporting of infants to the HRIIS. The first is a Regional Enhancement Program for the development of outreach methods to provide education, technical assistance and consultation to service providers in community hospitals and agencies around perinatal and high risk issues. The second is a Collaborative Perinatal System which has as one of its goals to establish a minimum NICU data set that integrates data required by the HRIIS and ensures that HRIIS data is reported in an accurate and timely manner to the MDPH.

D: Accuracy and Completeness of the HRIIS Data: Birth certificate linkage

A project is currently underway to match HRIIS data with birth certificate information for 1985 to estimate the extent of underreporting. This linkage is important because it allows us to:

@ evaluate the accuracy and completeness of the reporting of certain high risk criteria to the HRIIS;

@ validate HRIIS data which also appear on the birth certificate, namely: infant's name, date of birth, sex, gestational age in weeks, birthweight, hospital of birth, and mother's last name; and to

@ determine if the HRIIS has any reported infants for whom there are no corresponding birth certificates.

Although this particular matching process is being done primarily to determine the quality of reported data, plans are underway to incorporate birth certificate linkage with the High Risk system on a regular basis. Combining both data sets will enhance the HRIIS data and enrich its potential for such applications as a congenital anomaly surveillance system or for epidemiological analyses. An interim method of linking the two forms is being explored. Collaborative efforts between the Division of Health Statistics and Research and HRIIS staff are in process.

The publication of this Report provides the most current compilation of the HRIIS data. We have progressed toward a fuller understanding of the System's limitations and have noted where improvements can be made. We will continue in our efforts to upgrade the HRIIS. Our success depends on strong cooperation with hospital personnel who can be responsive to our need for accurate and timely reporting.

APPENDIX A

S 200

Chapter 557

THE COMMONWEALTH OF MASSACHUSETTS

In the Year One Thousand Nine Hundred and Eighty-five

AN ACT RELATIVE TO IDENTIFICATION AND TREATMENT OF CERTAIN PREMATURELY BORN INFANTS.

Whereas, The deferred operation of this act would tend to defeat its purpose, which is to immediately identify and treat certain prematurely born infants, therefore it is hereby declared to be an emergency law, necessary for the immediate preservation of the public convenience.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

SECTION 1. Chapter 111 of the General Laws is hereby amended by striking out section 67A, as appearing in the 1984 Official Edition, and inserting in place thereof the following section:-

Section 67A. Within ten days after the birth of any infant weighing twenty-five hundred grams or less or any infant with a high risk problem as defined by the department, each hospital or in the case of a birth outside of a hospital, the person responsible for delivery shall file a written notice of such birth on a form with the department. Said department shall promulgate rules which shall define the high risk problems and shall provide such reporting forms, and shall set forth the procedure to be followed when making such reports. An annual report shall be prepared on the status of premature and high risk infants. Such notices and reports shall be for the use of the department and its programs and shall not constitute a public record.

SECTION 2. Section sixty-seven B of said chapter one hundred and eleven is hereby repealed.

SECTION 3. Said chapter 111 is hereby further amended by striking out section 67C, as appearing in the 1984 Official Edition, and inserting in place thereof the following section:-

Section 67C. The department of public health shall provide programs for the prevention, care, and follow-up of premature and other designated high risk infants and establish criteria for services to be provided. The expenses for the transportation of said infants to hospitals equipped to care for them

and the expenses of initial hospitalization shall be paid by the department where such costs are not reimbursed by a third party payer. Said payments shall be made in accordance with rates established by the rate setting commission. Said payments shall be made only at the request of the parents or guardians of said infants to the department. The department shall apply financial eligibility guidelines to said programs and expenses.

SECTION 4. Section sixty-seven D of said chapter one hundred and eleven is hereby repealed.

SECTION 5. This act shall take effect on January first, nineteen hundred and eighty-six.

House of Representatives, November 21, 1985.

Preamble adopted, Mary Jane Gibson, Acting Speaker.

In Senate, November 22, 1985.

Preamble adopted, Gerard D Amico, Acting President.

House of Representatives, November 25, 1985.

Bill passed to be enacted, Robert Correia, Acting Speaker.

In Senate, November 25, 1985.

Bill passed to be enacted, William M. Bulger, Acting President.

December 5, 1985.

Approved,

at Four o'clock and 00 minutes, P. M.

Governor.

APPENDIX B1

HIGH RISK INFANT IDENTIFICATION

CONFIDENTIAL INFORMATION

THIS FORM MUST BE COMPLETED AT THE TIME OF TRANSFER, DISCHARGE OR DEATH FOR ALL INFANTS WHO MEET ONE OR MORE OF THE CRITERIA LISTED BELOW DURING THEIR HOSPITALIZATION. SEE LAST PAGE FOR INSTRUCTIONS TO FILL OUT THE FORM.

COMPLETED REPORTS ARE TO BE SENT TO: DEPARTMENT OF PUBLIC HEALTH
HIGH RISK INFANT IDENTIFICATION PROGRAM
150 TREMONT STREET, 2ND FLOOR
BOSTON, MA 02111

1. Date of Birth ☐☐/☐☐/☐☐

2. Name of Infant ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (Last) ☐☐☐☐☐☐☐☐☐☐☐☐ (First)

3. Sex: Male = M Female = F ☐

4. Gestational Age in Weeks ☐☐

5. Birthweight: ☐☐ lbs. ☐☐ ozs. or grams ☐☐☐☐

6. Hospital of Birth ____________________ ☐☐☐☐

7. Transferred to NICU: Yes = Y No = N ☐

8. Name of NICU ____________________ ☐☐☐☐

9. Criteria for Identification of High Risk Infants

- ☐ Birthweight less than or equal to 2500 grams (5 lbs. 8 ozs.)
- ☐ Severe growth retardation
- ☐ More than 24 hours in NICU
- ☐ Assisted ventilation for 24 hours or more
- ☐ Seizure(s) and/or neurologic abnormality
- ☐ Intraventricular or cerebral hemorrhage
- ☐ APGAR Score of 5 or less at 5 minutes
- ☐ Congenital anomaly(ies), describe: ____________________
- ☐ Exchange blood transfusion for hyperbilirubinemia
- ☐ Meningitis or congenital infection (please circle)
- ☐ A family member who has had a hearing loss since childhood
- ☐ Mother who has had rubella, toxoplasmosis, cytomegalovirus or herpes simplex II during pregnancy (please circle)

☐☐☐☐
☐☐☐☐
☐☐☐☐
☐
☐

10. Is Infant Living: Yes = Y No = N ☐

11. Reverse Transfer Out of NICU to Community Hospital: Yes = Y No = N ☐

12. Name of Community Hospital ____________________ ☐☐☐☐

13. Source of Primary Care/Medical Follow-up: Name ____________________

City/Town ____________________ ☐☐☐ Specialty ____________________ ☐☐

14. Follow-up Referrals: Early Intervention ____________________ ☐☐

VNA/PHN ____________________ ☐☐ Other ____________________ ☐☐

15. Name of Mother ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ (Last) ☐☐☐☐☐☐☐☐☐☐☐☐ (First)

16. Home Address ____________________ ☐☐☐ 17. Home Phone ☐☐☐☐☐☐☐

18. Date of Infant Discharge:

☐☐/☐☐/☐☐ From Birth Hospital ☐☐/☐☐/☐☐ From NICU ☐☐/☐☐/☐☐ From Community Hospital

19. Discharge Other Than to Parent(s): Yes = Y No = N ☐

20. Signature of Person Completing Form ____________________

APPENDIX B2

HIGH RISK INFANT IDENTIFICATION

Confidential Information

THIS FORM MUST BE COMPLETED AT THE TIME OF TRANSFER, DISCHARGE OR DEATH FOR ALL INFANTS WHO MEET ONE OR MORE OF THE CRITERIA LISTED BELOW DURING THEIR HOSPITALIZATION. SEE LAST PAGE FOR INSTRUCTIONS TO FILL OUT THE FORM

COMPLETED REPORTS ARE TO BE SENT TO: DEPARTMENT OF PUBLIC HEALTH
HIGH RISK INFANT IDENTIFICATION SYSTEM
150 TREMONT STREET, 2ND FLOOR
BOSTON, MA 02111

INFANT

1. Name of infant (Last) (First)
2. Date of birth __/__/__ 3. Birthweight __ lbs. __ ozs. OR grams __
4. Gestational age in weeks __ 5. Sex Male __ Female __
6. Hospital of birth __________

MOTHER

7. Name of mother (Last) (First)
8. Home address (#, street, apt.)
(City/Town) (Zipcode)
9. Source of payment for infant's bills: Parent(s) __ Medicaid __ BC/BS __ Other __________

CRITERIA FOR IDENTIFICATION OF HIGH RISK INFANTS

10.
- ☐ Birthweight less than or equal to 2500 grams (5 lbs. 8 ozs.)
- ☐ Birthweight less than 10th percentile for gestational age (SGA)
- ☐ More than 48 hours in NICU; reason: __________
- ☐ APGAR score of 5 or less at 5 minutes
- ☐ Mechanical ventilation (intubation) for 24 hours or more
- ☐ Seizure(s)
- ☐ Intracranial hemorrhage
- ☐ Neurologic abnormality (palsy, abnormal tone, etc.): __________
- ☐ Exchange blood transfusion for hyperbilirubinemia
- ☐ Congenital or perinatal infection: (specify) Rubella __ Toxoplasmosis __ Cytomegalovirus __
  Herpes __ Syphilis __ Meningitis __ Other __________
- ☐ Congenital anomaly(ies), describe: __________
- ☐ Mother who had an active infection during pregnancy: (specify)
  Rubella __ Toxoplasmosis __ Cytomegalovirus __ Genital Herpes __
- ☐ Family member (blood relative) who has had a hearing loss since childhood

DISCHARGE AND TRANSFER

11. Date of discharge or transfer from BIRTH HOSPITAL __/__/__ Medical Record# ______
12. Transferred to NICU or other ICU? No __ Yes __
Name of NICU/ICU __________
Date of discharge or transfer from NICU/ICU __/__/__ Medical Record# ______
13. Transferred from NICU/ICU to COMMUNITY HOSPITAL or NORMAL NURSERY? No __ Yes __
Name of COMMUNITY HOSPITAL or NORMAL NURSERY __________
Date of discharge from Community Hospital/Normal Nursery __/__/__
Medical Record# ______
14. Is infant living? No __ Yes __
15. At final hospital discharge, was infant sent home to parent(s)? No __ Yes __

FOLLOW-UP

16. Source of primary pediatric care (name of MD or facility) __________
17. Referrals: Community Nursing Agency (specify) __________
Early Intervention Program (name) __________
Other medical or social service referrals (specify) __________
18. SIGNATURE OF PERSON COMPLETING FORM __________

Mass. DPH

copy 1: to be completed by hospital of birth

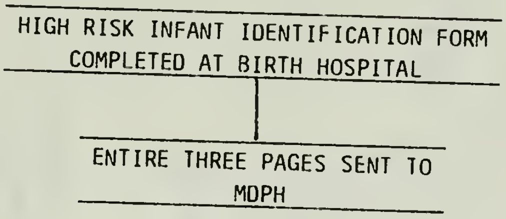
FORM # 176757

APPENDIX C

FLOW CHART OF REPORTING PROCESS

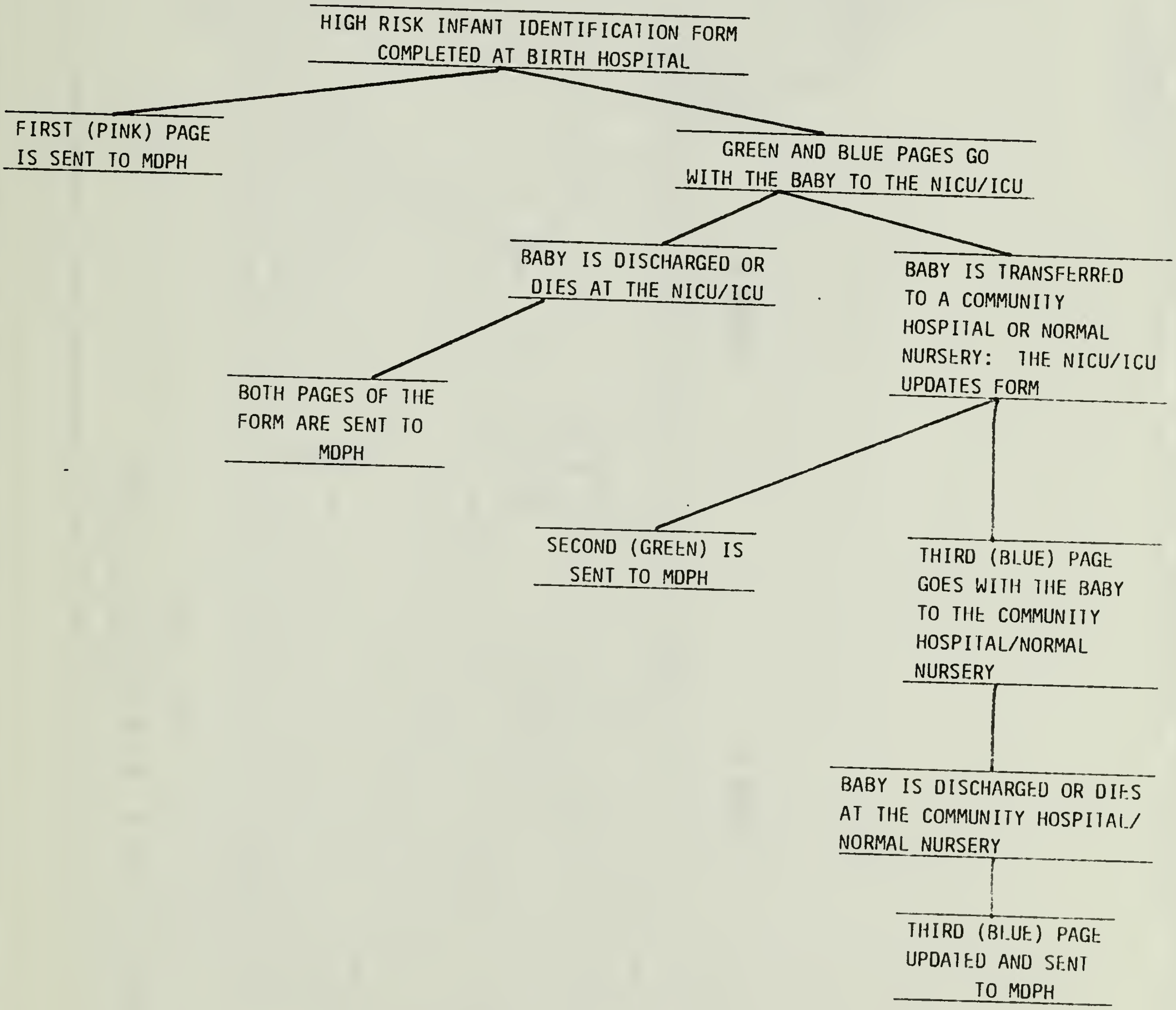
Example A:

INFANT IS IDENTIFIED AS HIGH RISK AND IS DISCHARGED FROM THE BIRTH HOSPITAL TO THE PARENT OR GUARDIAN.

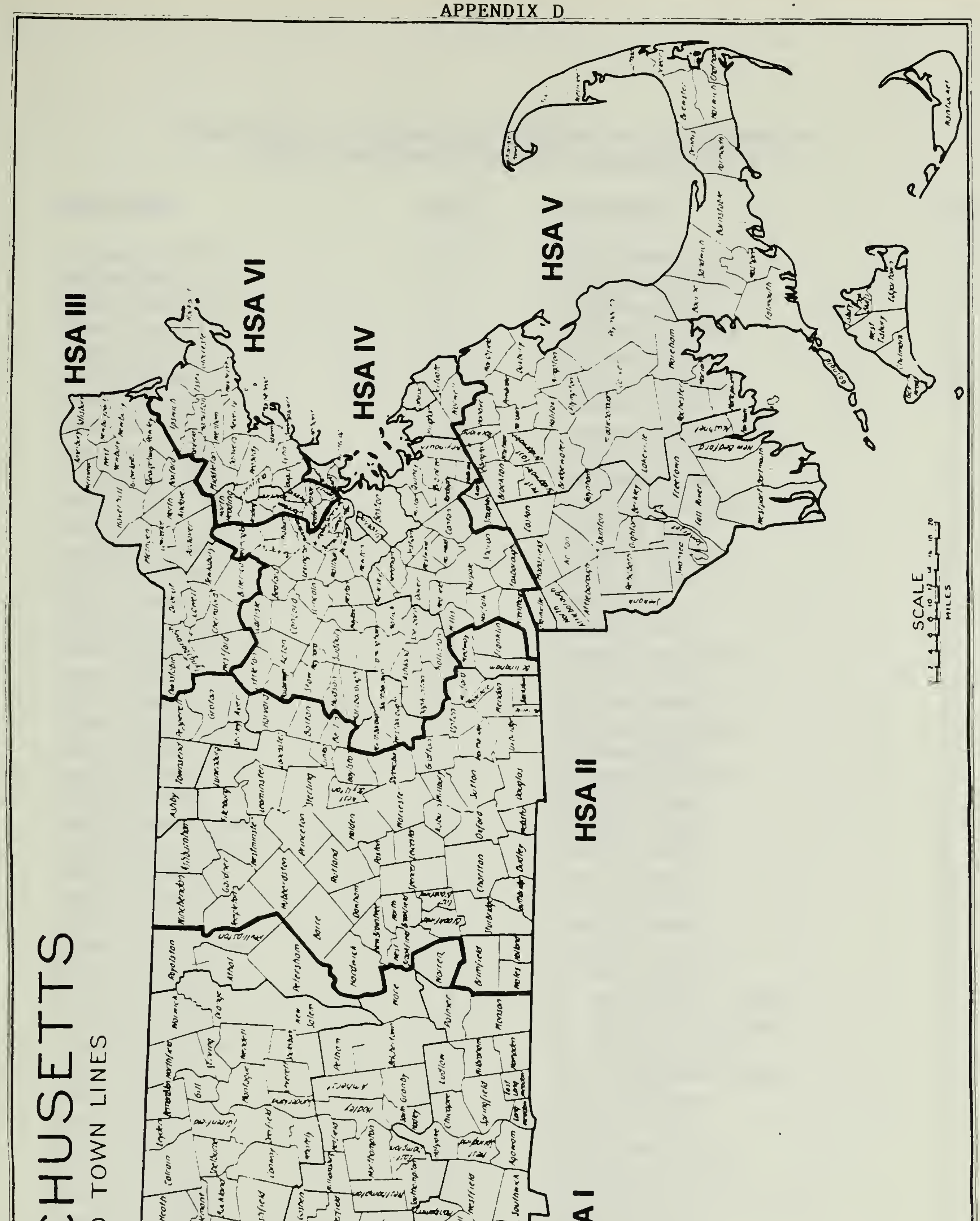


Example B:

INFANT IDENTIFIED AS HIGH RISK AND IS TRANSFERRED TO ANOTHER HOSPITAL OR NEWBORN UNIT



APPENDIX D


MASSACHUSETTS
CITY AND TOWN LINES
HSA I
HSA II
HSA III
HSA IV
HSA V
HSA VI
SCALE
MILES

Appendix D: Alphabetical Listing of Massachusetts Cites and Towns with Corresponding HSA's

TOWN NAME	HSA
Abington Town	5
Acton Town	4
Achushnet Town	5
Adams Town	1
Agawam Town	1
Alford Town	1
Amesbury Town	3
Amherst Town	1
Andover Town	3
Arlington Town	4
Ashburnham Town	2
Ashby Town	2
Ashfield Town	1
Ashland Town	4
Athol Town	1
Attleboro City	5
Auburn Town	2
Avon Town	5
Ayer Town	2
Barnstable Town	5
Barre Town	2
Becket Town	1
Bedford Town	4
Belchertown Town	1
Bellingham Town	2
Belmont Town	4
Berkley Town	5
Berlin Town	2
Bernardston Town	1
Beverly City	6
Billerica Town	3
Blackstone Town	2
Blandford Town	1
Bolton Town	2
Boston City	4
Bourne Town	5
Boxborough Town	4
Boxford Town	3
Boylston Town	2
Braintree Town	4
Brewster Town	5
Bridgewater Town	5
Brimfield Town	2
Brockton City	5
Brookfield Town	2
Brookline Town	4
Buckland Town	1
Burlington Town	4
Cambridge City	4
Canton Town	4
Carlisle Town	4
Carver Town	5
Charlemont Town	1
Charlton Town	2
Chatham Town	5
Chelmsford Town	3
Chelsea City	4
Cheshire Town	1
Chester Town	1
Chesterfield Town	1
Chicopee City	1
Chilmark Town	5
Clarksburg Town	1
Clinton Town	2
Cohasset Town	4
Colrain Town	1
Concord	4
Conway Town	1
Cummington Town	1
Danvers Town	6
Dalton Town	1
Dartmouth Town	5
Dedham Town	4
Deerfield Town	1
Dennis Town	5
Dighton Town	5
Douglas Town	2
Dover Town	4
Dracut Town	3
Dudley Town	2
Dunstable Town	3
Duxbury Town	5
E. Bridgewater Town	5
E. Brookfield Town	2
E. Hampton Town	1
E. Longmeadow Town	1
Eastham Town	5
Easton Town	5
Edgartown Town	5
Egremont Town	1
Erving Town	1
Essex Town	6
Everett City	6
Fairhaven Town	5
Fall River City	5
Falmouth Town	5
Fitchburg City	2
Florida Town	1
Foxborough Town	4
Framingham Town	4
Franklin Town	2
Freetown Town	5
Gayhead Town	5
Gardner City	2

Appendix D: Alphabetical Listing of Massachusetts Cites and Towns with Corresponding HSA's

TOWN NAME	HSA
Georgetown Town	3
Gill Town	1
Gloucester City	6
Goshen Town	1
Gosnold Town	5
Grafton Town	2
Granby Town	1
Granville Town	1
Great Barrington Town	1
Greenfield Town	1
Groton Town	2
Groveland Town	3
Hadley Town	1
Halifax Town	5
Hamilton Town	6
Hampden Town	1
Hancock Town	1
Hanover Town	5
Hanson Town	5
Hardwick Town	2
Harvard Town	2
Harwich Town	5
Hatfield Town	1
Haverhill City	3
Hawley Town	1
Heath Town	1
Hingham Town	4
Hinsdale Town	1
Holbrook Town	4
Holden Town	2
Holland Town	2
Holliston Town	4
Holyoke CIty	1
Hopedale Town	2
Hopkinton Town	4
Hubbardston Town	2
Hudson Town	4
Hull Town	4
Huntington Town	1
Ipswich Town	6
Kingston Town	5
Lakeville Town	5
Lancaster Town	2
Lanesborough Town	1
Lawrence City	3
Lee Town	1
Leicester Town	2
Lenox Town	1
Leominster City	2
Leverett Town	1
Lexington Town	4
Leyden Town	1
Lincoln Town	4
Littleton Town	4
Longmeadow Town	1
Lowell City	3
Ludlow Town	1
Lunenburg Town	2
Lynn City	6
Lynnfield Town	6
Malden City	6
Mansfield Town	5
Manchester	6
Marblehead Town	6
Marion Town	5
Marlborough City	4
Marshfield Town	5
Mashpee Town	5
Mattapoisett Town	5
Maynard Town	4
Medfield Town	4
Medford City	6
Medway Town	2
Melrose City	6
Mendon Town	2
Merrimac Town	3
Methuen Town	3
Middleborough Town	5
Middlefield Town	1
Middleton Town	6
Milford Town	2
Millbury Town	2
Millis Town	4
Millville Town	2
Milton Town	4
Monroe Town	1
Monson Town	1
Montague Town	1
Monterey Town	1
Montgomery Town	1
Mount Washington Town	1
Nahant Town	6
Nantucket Town	5
Natick Town	4
Needham Town	4
New Ashford Town	1
New Bedford Town	5
New Braintree Town	2
New Marlborough Town	1
New Salem Town	1
Newbury Town	3
Newburyport City	3
Newton City	4
Norfolk Town	4

Appendix D: Alphabetical Listing of Massachusetts Cites and Towns with Corresponding HSA's

TOWN NAME	HSA	TOWN NAME	HSA
North Adams Town	1	Sandwich Town	5
North Andover Town	3	Saugus Town	6
North Attleborough Town	5	Savoy Town	1
North Brookfield Town	2	Scituate Town	4
North Reading Town	6	Seekonk Town	5
Northampton City	1	Sharon Town	4
Northborough Town	4	Sheffield Town	1
Northbridge Town	2	Shelburne Town	1
Northfield Town	1	Sherborn Town	4
Norton Town	5	Shirley Town	2
Norwell Town	4	Shrewsbury Town	2
Norwood Town	4	Shutesbury Town	1
Oak Bluffs Town	5	Somerset Town	5
Oakham Town	2	Somerville City	4
Orange Town	1	South Hadley Town	1
Orleans Town	5	Southampton Town	1
Otis Town	1	Southborough Town	4
Oxford Town	2	Southbridge Town	2
Palmer Town	1	Southwick Town	1
Paxton Town	2	Spencer Town	2
Peabody City	6	Springfield City	1
Pelham Town	1	Sterling Town	2
Pembroke Town	5	Stockbridge Town	1
Pepperell Town	2	Stoneham Town	6
Peru Town	1	Stoughton Town	5
Petersham Town	1	Stow Town	4
Phillipston Town	1	Sturbridge Town	2
Pittsfield City	1	Sudbury Town	4
Plainfield Town	1	Sunderland Town	1
Plainville Town	5	Sutton Town	2
Plymouth Town	5	Swampscott Town	6
Plympton Town	5	Swansea Town	5
Princeton Town	2	Taunton City	5
Provincetown Town	5	Templeton Town	2
Quincy City	4	Tewksbury Town	3
Randolph Town	4	Tisbury Town	5
Raynham Town	5	Tolland Town	1
Reading Town	6	Topsfield Town	6
Rehoboth Town	5	Townsend Town	2
Revere City	4	Truro Town	5
Richmond Town	1	Tyngsborough Town	3
Rochester Town	5	Tyringham Town	1
Rockland Town	5	Upton Town	2
Rockport Town	6	Uxbridge Town	2
Rowe Town	1	Wakefield Town	6
Rowley Town	3	Wales Town	2
Royalston Town	1	Walpole Town	4
Russell Town	1	Waltham City	4
Rutland Town	2	Ware Town	1
Salem City	6	Wareham Town	5
Salisbury Town	3	Warren Town	1
Sandisfield Town	1	Warwick Town	1

Appendix D: Alphabetical Listing of Massachusetts Cites and Towns with Corresponding HSA's

TOWN NAME	HSA
Washington Town	1
Watertown Town	4
Wayland Town	4
Webster Town	2
Wellesley Town	4
Wellfleet Town	5
Wendell Town	1
Wenham Town	6
West Boylston Town	2
West Bridgewater Town	5
West Brookfield Town	2
West Newbury Town	3
West Springfield Town	1
West Stockbridge Town	1
West Tisbury Town	5
Westborough Town	4
Westfield City	1
Westford Town	3
Westhampton Town	1
Westminster Town	2
Weston Town	4
Westport Town	5
Westwood Town	4
Weymouth Town	4
Whately Town	1
Whitman Town	5
Wilbraham Town	1
Williamsburg Town	1
Williamstown Town	1
Wilmington Town	4
Winchendon Town	2
Winchester Town	4
Windsor Town	1
Winthrop Town	4
Woburn City	4
Worcester City	2
Worthington Town	1
Wrentham Town	4
Yarmouth Town	5

Appendix E: Alphabetical Listing of Massachuetts Maternity Hospitals and Corresponding HSAs

HOSPITAL	HSA	HOSPITAL	HSA
Addison Gilbert	6	Lowell General	3
Anna Jacques	3	Lynn	6
Baystate Medical	1	Malden	6
Berkshire Medical	1	Martha's Vineyard	5
Beth Israel	4	Mary Lane	1
Beverly	6	Melrose-Wakefield	6
Bon Secours	3	Milford-Whitinsville	2
Boston City	4	Morton	5
Brigham & Women's	4	Mount Auburn	4
Brockton	5	Nantucket Cottage	5
Burbank	2	New England Memorial	6
Cambridge	4	Newton Wellesley	4
Cape Cod	5	North Adams	1
Charlton Memorial	5	Norwood	4
Cooley Dickenson	1	Providence	1
Emerson	4	Quincy	4
Fairview	1	St. Elizabeth's	4
Falmouth	5	St. Joseph's	3
Framingham	4	St. Luke's	5
Franklin	1	St. Margaret's	4
Goddard Memorial	5	St. Vincent	2
Harrington Memorial	2	Salem	6
Haverhill	3	South Shore	4
Henry Heywood	2	Sturdy Memorial	5
Hunt	6	Tobey	5
Jordan	5	Waltham	4
Lawrence General	3	Winchester	4
Leominster	2	Worcester Hahneman	2
Leonard Morse	4	Worcester Memorial	2

Alphabetical Listing of Massachuetts Neonatal Intensive Care Units (NICUs) and Corresponding HSA's

NICU	HSA
Baystate Medical Center	1
Boston City Hospital	4
Brigham and Women's Hospital	4
Children's Hospital Medical Center	4
Massachusetts General Hospital	4
New England Medical Center	4
St. Margaret's Hospital	4
Worcester Memorial Hospital	2

APPENDIX F

The Commonwealth of Massachusetts
Executive Office of Human Services
Department of Public Health
Division of Family Health Services
150 Tremont Street, Boston 02111
(617) 727-5121

Michael S. Dukakis
Governor

Philip W. Johnston
Secretary

borah Prothrow-Stith, M.D.
Commissioner

Dear Parent,

You may recall that at the time of your child's birth you were given information (in a blue brochure) on a program called the <u>Hearing Evaluation Program for Infants and Toddlers</u>. Through this program, infants and young children thought to be at risk for hearing loss are given thorough hearing evaluation/s by audiologists in centers approved by the Department of Public Health to provide these specialized services.

We are committed to the early identification of hearing problems in very young children and assure you that <u>once registered by telephone with the Department</u>, there will be <u>no out-of-pocket expenses to the family</u>. Medicaid or private insurance will be billed, if available to you. However, if rejected or only partially paid, the Department will accept responsibility for payment.

The Department has identified seven (7) criteria thought to place a child at risk for hearing loss:

1. Family member with hearing loss <u>since childhood</u>
2. Mother who had German measles, cytomegalovirus, toxoplasmosis, or herpes simplex II during pregnancy.
3. Child who: Had a birth weight of 1800 grams (4 lbs. or less).
4. Had meningitis, a congenital or perinatal infection (german measles, cytomegalovirus, toxoplasmosis or Herpes).
5. Required assisted ventilation (oxygen) for 24 hours or more.
6. Had an exchange blood transfusion for severe jaundice.
7. Had an APGAR score of <u>5 or less</u> at 5 minutes.
8. Anything unusual about the ear, head or neck. For example: cleft lip/palate Down's Syndrome, etc.

Your baby's record indicates # _____ (circled above) and he/she is therefore eligible for services through this program. We encourage you to call for information and/or to register your child for hearing evaluations. <u>PLEASE CALL</u>.

We look forward to hearing from you.

Sincerely,

Alice T. Morrison
Program Director

ATM/Ro

Appendix G: Abbreviations for HRIIS Criteria

Criteria as listed on HRIIS Form	Abbreviation
Birthweight less than or equal to 2500 grams	BWT $\leq$ 2500gms
Severe Growth Retardation	SGA/IUGR
More than 24 hours in NICU	NICU $>$ 24 hrs
Assisted Ventilation for 24 hours or more	Asst. Vent. or Assisted Ventilation
Seizure(s) and or neurologic abnormality	Seizures
Intraventricular or cerebral hemorrhage	Cerebral Hem or Hemorrhage
APGAR score of 5 or less at 5 minutes	5 min APGAR $<$ 5
Congenital Anomaly	Cong. (or Congenital) Anomaly
Exchange Blood Transfusion for Hyperbilirubinemia	Blood Transfusion
Meningitis or Congenital Infection	Cong. (or Congenital) Infection
A Family History of Hearing Loss Since Childhood	Fam Hx Hearing Loss
Mother who had Rubella, Toxoplasmosis, Cytomegalovirus or Herpes Simplex II during Pregancy	Maternal Infection

Appendix H: Glossary of Terms

Birth Hospital	Hospital of infant's birth. At a Perinatal Center with a NICU, birth hospital refers to the Labor and Delivery Unit.
Community Hospital	Level I or II hospitals or a normal newborn nursery (NNB) within a level III perinatal center. High-risk newborns sometimes convalesce or recover in NNB's.
Congenital Anomaly	Absence or excess of a biochemical substance, tissue, organ, part of the body or bodily function, existing, but not always apparent at birth, including: structural malformations, chromosomal abnormalities, genetic diseases, and inborn errors of metabolism.
DFHS	Division of Family Health Services.
EIP	Early Intervention Program: an organized system of services for infants and toddlers aged birth to three years and their families which meets the requirements of the Department of Public Health's Operational Standards for Early Intervention Programs.
High Risk Infant	An infant who has special risks for adjustment to extrauterine life, health, or survival and is likely to require specialized neonatal care and/or follow-up services.
HRIIS	High Risk Infant Identification System: a legally mandated reporting system which identifies newborn infants who are Massachusetts residents and are considered to be at risk for neurological, physical and developmental dysfunction.
HSA	In accordance with the National Health Planning and Resources Development Act of 1974 (P.L. 93-641), Massachusetts is divided into six Health Service Areas (HSAs) for the purpose of planning and developing health services. Each HSA encompasses both metropolitan and non-metropolitan areas and contains at least one center for the provision of highly specialized health services.
Low birth weight	Birthweight less than or equal to 2500 grams (5 lbs. 8 ozs.)
Live born	The complete expulsion or extraction of the mother's product of conception, regardless of the duration of pregancy, which, after separation, breaths or shows any other signs of life, such as beating of heart, pulsation of umbilical cord, or definite movement of voluntary muscles.

MCH	Maternal and Child Health or Maternal and Child Health Section of the Division of Family Health Services.
MDPH	Massachusetts Department of Public Health
NICU	Neonatal Intensive Care Unit. A Level III licensed nursery. There are eight such nurseries in Massachusetts.
Perinatal Center	A Level III facility which provides care and services to mothers and newborns ranging from uncomplicated to high-risk, including those with unusual or severe complications or anomalies. Offers a comprehensive range of specialty and subspeciality services to maternal patients from the center or referred from Level I-II services. Has the capabilities to manage the maternal patient requiring intensive care. Maintains a NICU.
Referral	A direct contact with a community agency indicating the need for community follow-up of the high-risk infant.
Tertiary Care Unit	Those acute care units which are licensed as level III nurseries.
Transfer Infant	Any infant who is transferred from the birth hospital, because he/she requires the diagnostic and treatment capabilities of a more acute-level facility. (For Perintal Centers a baby is considered as transferred from a Birth Hospital when an in-born baby is admitted to an in-house NICU.)

* * * * * *

Anencephaly	a disorder of neural tube closure at the anterior end in which there is a partial or complete absence of the calvarium and cranial vault with the cerebral hemispheres missing or greatly reduced. This defect is incompatible with protracted postnatal life.
Cleft Lip	failure of fusion of three mesodermal processes (lateral nasal, median nasal and maxillary) which can be complete or partial, bilateral or unilateral.
Cleft Palate	failure of fusion of palatal shelves which can be complete or partial, and vary in size and location.
Down Syndrome	a combination of birth defects and mental retardation resulting from three copies, instead of the normal two, of chromosome number 21.
Hip Dislocation	Displacement of the hip such that there is a disturbance in the normal relation of the bones entering into the formation of a joint.

Hydrocephalus	an excess of fluid volume in the ventricles of the brain, resulting from an imbalance in the amount of cerebrospinal fluid secreted and absorbed; usually accompanied by an increase in intracranial pressure.
Hypospadias	abnormal location of an urethral opening on the under surface of the penis.
Limb Reduction	absence of any part of any limb.
Rectal/Anal Atresia	Absence of the terminal portion of the digestive tube to the anal canal or the anal canal itself or; absence of an opening from the anal canal to the outside of the body.
Spina Bifida	a disorder of neural tube closure in the caudal section in which arches of the vertebrae fail to fuse, producing a sac-like protrusion through the opening.